

PROCESSES OF COMMUNICATION ABOUT CANCER

IN A RADIOTHERAPY DEPARTMENT

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ABSTRACT

The study was concerned with ongoing processes of communication about cancer. It was carried out in a single Department of Radiotherapy with a mixed population of cancer patients, the vast majority of whom were undergoing active treatment. Central to the study was an examination of how patients, their families and hospital staff managed communication about the illness in interaction with each other, particularly methods of information seeking and control as these related to states of awareness about diagnosis and prognosis. Attention was also given to how doctors and nurses managed information about patients among themselves.

An interactionist perspective was taken and the methods used derived from grounded theory. Data were collected by means of different forms of observation and interviewing together with a questionnaire to relatives. Analysis took both qualitative and quantitative forms. Qualitative in the sense of describing communication practices between participants and the processes observed to occur and from this deducing explanations. Quantitative analysis was performed on various aspects of nurse patient interaction and communication as well as on contact between relatives and hospital staff and the awareness states exhibited by relatives.

The findings demonstrate the powerful explanatory value of uncertainty for both the restrictive communication practices engaged in by doctors and nurses and the selective information seeking and avoidance observed in patients and their relatives within both the formal and informal communication networks. Analysis of nurse patient interactions showed a marked emphasis on physical aspects of care together with an avoidance of exploring patients' personal characteristics including their response to their illness. The

implications of current communication practices are discussed for patients adjusting to cancer in different ways, for relatives who may require assistance to cope with the concomitants of the illness and for nurses by way of developing more patient oriented methods of communication.

I declare that this Thesis is my
own work.

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PREFACE

The paucity of research on communication with cancer patients is an indication not only of the infinite complexity of the subject matter but of its connotations. Not uncommonly explanations about the study were reinterpreted by listeners as a study of dying patients and therefore distasteful, depressing and morbid. In fact the study was concerned with contributing to knowledge which may be used to underwrite the nursing care of patients living with cancer as well as that of their family.

As the study progressed different streams of thought influenced conceptualisation and analysis of the problem of communication about cancer. Some ideas which seemed important at the beginning became less relevant while others emerged into prominence. Doing this study provided the opportunity to explore how the ideas of others may apply in this particular situation and this has proven to be an enriching experience. Not all of the issues have been included in this final report.

The thesis follows a sequence through some relevant literature, methods employed in the study, analysis of communication by doctors, nurses, patients and their families, to the final recommendations. By focussing sequentially on the different categories of participant, as well as simplifying presentation of complex data, this format was intended to allow for independent consideration of any particular group. It is to be hoped that this format does not interfere with the essentially interactive nature of the subject matter.

It was difficult to decide how much original data to include which should not be merely anecdotal but used in consideration of some theoretical or practical issue. If anything, I have probably erred on the side of over inclusion of observation and quotation in

an attempt to reveal the source of theory development. It is to be hoped that this is enriching rather than interfering excessively with readability.

Another issue in presentation concerned points relevant to nurse education which arose all the way through. It was decided to include a short chapter on how nurses learned about managing communication after the relevant nursing chapters. Some of the wider issues are brought together in the final chapter.

This study arose from personal experience of working with cancer patients which indicated that communication was a problem of sufficient magnitude to warrant investigation. It was begun with a minimum of experience of the methods used and theoretical stance from which they derived and regarded as an exploration in theory development rather than theory testing. In no sense therefore can it be regarded as a definite ^{ive} analysis of communication about cancer but as a basis for the development of further work.

CHAPTER 1

THE PROBLEM EXAMINED THROUGH LITERATURE

This study was undertaken in an attempt to extend understanding of communication between nurses and cancer patients and their families. Experience of nursing and reviewing the literature had shown that there were serious gaps in research findings which influenced the availability of teaching material and, hence, nurses' understanding of their practices. The study describes and explains communication in one Radiotherapy Department, focussing on the management of interaction and communication by doctors and nurses and information seeking by cancer patients and their families.

A considerable volume of literature, if not research, is available which impinges on one or more facets of the problem.⁽¹⁾ To consider all of this would be an enormous task and what is presented here is necessarily selective. Theoretical justification and some key concepts are delineated. This chapter considers cancer as a culturally defined phenomenon and then proceeds to consider nurses' communication. The following chapter concentrates on patients and their families.

The Meaning of Cancer

Weisman writes

'to most people cancer is a paradigm of fatal disease. Research and treatment continue to be encouraging but the diagnosis itself has grim and persistent implications that prejudice our judgment of what being sick with cancer implies' (2, p.97).

Jason⁽³⁾ reports that cancer implies 'the kiss of death', 'deadly', 'hidden', 'insidious', 'it eats all the way through', and Marmer⁽⁴⁾ considered the emotional threat entailed by cancer to be as great as its physical manifestations, calling it 'emotional catastrophe'.

Such connotations are not surprising considering the facts. In Scotland, almost thirteen and a half thousand people die of cancer annually, representing one fifth of all deaths.⁽⁵⁾ District nurses have reported the suffering, both physical and mental, experienced by the majority of patients.⁽⁶⁾ A recent survey showed 87 per cent of people dying from cancer reported pain, often of a distressing nature, during the course of their illness.⁽⁷⁾

Although cancer is many diseases with associated variability of prognosis, response to treatment, rate and likelihood of metastasing and physical manifestations, such differences are not readily acknowledged. Easson⁽⁸⁾ and Davison⁽⁹⁾ have reported generally pessimistic attitudes among doctors and nurses. Parkes⁽¹⁰⁾ attributes their distress to regular exposure to the often terrible consequences of cancer and limitations in treatment.

The culturally held meaning of cancer is a powerful determinant of behaviour and is strongly reflected in patients by, for example, a reluctance to seek help when cancer is suspected,^(11,12) in 'forgetting' when the diagnosis has been imparted⁽¹³⁾ and in denying the severity of the illness when to others it is obvious.⁽¹⁴⁾ Doctors are reluctant to impart diagnostic information to cancer patients despite the recognised advantages in giving patients information about other conditions.⁽¹⁵⁾

Literature on the debate about 'whether to tell the patient' could fill many volumes but most is based on opinion and individual experiences rather than systematic investigation with verified evidence. The evidence which is available indicates that doctors in Britain prefer not to inform patients when they have cancer. A recent study of patients with lung cancer in Scotland⁽¹⁶⁾ reports 'In this survey the chest physician found no reason to divulge the diagnosis to the patient'.

Cartwright et al.⁽¹⁷⁾, Ward⁽¹⁸⁾ and McIntosh⁽¹⁹⁾ found doctors withholding information from patients about a cancer diagnosis as they did about prognosis and impending death. Nurses are even more reluctant to impart information about their condition to cancer patients.^(20,21) Quint⁽²²⁾ attributes nurses' conversational difficulties and control of information to feelings of helplessness and hopelessness generated by the association between cancer and death. Attempts to avoid such negative emotion give rise to institutionalised practices of information control.

Given the pervasive despondency about cancer and its strong association with death, it is not surprising that few first hand studies have been conducted involving cancer patients in hospital but McIntosh⁽²³⁾ has recently published a study conducted in Scotland. In one of the few nursing studies, Quint⁽²⁴⁾ in the United States described how the nurse researchers had to work through their own feelings about breast cancer as the study progressed.

The meaning that cancer holds for the individuals concerned is likely to exert a pervasive influence on communication. How this operates among patients and hospital staff was one of the issues examined in the study.

Nurses as Communicators

The focus in this study was on communication about the patients' illness. Studies in different settings and irrespective of the nature of the diagnosis⁽²⁵⁻²⁷⁾ have shown nurses to fall into the category labelled by Sudnow⁽²⁸⁾ as 'non-announcer'. Beliefs among nurses and doctors that responsibility for decision making and imparting diagnosis and prognosis lies with the doctor is amply reinforced in nursing literature. In a British text book on cancer nursing, regarding

informing patients, it is written:

'...it should be dealt with by the doctor who is giving treatment and the decision as to whether to inform the patient or not should be his.' (29, p.74)

Holthouse, a senior nurse in a cancer hospital wrote:

'...obviously it is the doctor's place to explain what he considers the patient ought to know about his condition and prognosis.' (30, p.45)

Quint writes:

'...physicians are the legitimate definers of the patient's diagnostic identity, whereas nurses are expected to support physicians in their decisions to withhold or to give particular kinds of information. In effect, the nurses are supported in their individual and group manoeuvres by a professional rationale which affirms that only the physician can disclose a patient's diagnosis to him.' (31, p.128)

This rationale is demonstrated by Roberts⁽³²⁾ and borne out in McIntosh's study of communication in a cancer ward.⁽³³⁾

Cartwright et al.⁽³⁴⁾ report that only 6 per cent of district nurses and health visitors, if asked for a prognosis by a dying patient, say that they 'would tell him the truth gently' while only 2 per cent consider a nurse the best person to disclose prognosis. Thompson and Sidman⁽³⁵⁾ found that nurses were confident of their abilities to give cancer patients information about their illness, but doctors expressed doubts about nurses' ability both to give information and provide emotional support through discussion of concerns. Duff and Hollingshead⁽³⁶⁾ found a similar difference between doctors' and nurses' beliefs, but in practice found nurses imparted little information and knew little of patients' emotional response to their illness.

The categories of information involved extend beyond diagnosis and prognosis and it is apparent that situational and contextual variables will determine the information which nurses may legitimately impart. Harrison reports, for instance, the ward sister as the most

regular source of information to parents about Perthes disease⁽³⁷⁾

and Houghton writes of maternity hospitals:

'Traditionally the ward sister has been regarded as the most important person to give information.' (38, p.129)

Cartwright et al. report that 33 per cent of relatives of patients who died discussed the illness and outcome with a hospital nurse⁽³⁹⁾ and in another study by Cartwright⁽⁴⁰⁾ over a quarter of patients reported the ward sister as the main source of information and a further 4 per cent involved other nurses. Seventy per cent of patients, however, said they got no information from nurses. The question Cartwright asked involved whether patients had received information about 'illness, treatment and progress' and, unfortunately, in none of these studies was there any indication of the type or quality of information involved.

Widespread evidence exists, however, that nurses impart little information to patients about particular aspects of their condition. Roberts⁽⁴¹⁾ for instance reports of patients discharged from hospital only 11 per cent had received 'very specific advice and instructions' and of all patients receiving advice, only one quarter reported a nurse being involved. Patients discharged after coronary heart disease also report nurses as being unlikely to give information related to post-discharge care and rehabilitation.⁽⁴²⁾ Nurses avoided conversation about treatment,⁽⁴³⁾ the significance of symptoms⁽⁴⁴⁾ and the many tests conducted on patients with cancer.⁽⁴⁵⁾ Quint reported:

'that nurses do not openly initiate discussion about mastectomy and its personal meanings is the rule, not the exception'. (46, p.265)

Nurses may impart information informally however, rather than formally. Although least informed of some aspects of the patients' condition, it is sometimes the most junior nurses who inadvertently

convey information to patients because they have not yet learned how to control expression and other behavioural cues by adopting a well conditioned institutionalised manner. Quint⁽⁴⁷⁾ found students engaging in open encounters with dying patients prone to 'conversational blunders' which unwittingly contributed to the patient's knowledge of what was going on. Katz⁽⁴⁸⁾ observed also that well socialised nurses, in contrast with student nurses, were apt to feel 'quite at home' when telling a terminally ill patient that he would get better and that he should certainly ask the doctor about prognosis.

The nature of the illness, traditional role distinctions and informal institutional rules prohibiting nurses from imparting certain categories of information to cancer patients can be expected to determine to some extent nurses' formal communication practices. This leaves questions, however, about how nurses manage communication with patients, the nature of information imparted and whether situational variables influence their informal practices.

Influences of Organisation and Work

Skipper asserts that:

'the structure of the modern hospital is not organised toward meeting patients' needs for communication but is dedicated to the more 'action oriented' ends of caring for and curing patients.' (49, p.74)

Organisational features pointed out by Quint⁽⁵⁰⁾ as responsible for maximising patients' difficulties in seeking information included the use of routines, rotating nurses assignments and group rounds all of which diminished the length of contact between individual patients and members of staff. Furthermore, lack of clear cut delegation of responsibility for specific aspects of care enhanced 'passing the buck' and the management of activities to give an atmosphere of business with primacy given to life saving activities. Menzies⁽⁵²⁾ as well as

Quint⁽⁵³⁾ have attributed such activities to endeavours to split up the nurse-patient relationship.

Not all wards display identical characteristics of organisation, however, nor is stress always laid on life saving activity. Sudnow⁽⁵⁴⁾ found different organisational features associated with wards differentially characterised by high or low death rates. Quint⁽⁵⁵⁾ observed how spatial organisation of wards influenced how nurses communicated such that all patients were grouped together and visiting was restricted where minimisation of conversational contacts occurred. Those unconcerned with limiting conversation had one or few patients to a room and permissive visiting.

Not only the organisational context, but the nature of nurses' work within it, influences communication.

Barnes wrote:

'General hospital personnel are characteristically action minded. The very nature of their work demands action without much thought, their whole approach to any kind of problem is to do something, and the telling seems to be forgotten in the doing'. (56,p16)

Doing traditionally relates to physical tasks and is characterised in studies of nursing using work study methods where activities are classified as basic, technical, administrative and so on.⁽⁵⁷⁾ Similarly when patients are placed into categories as a basis for calculating nursing workload it is typically along physical dimensions,⁽⁵⁸⁾ and the physical and psychosocial needs of patients do not necessarily correlate.

This limited conceptualisation of nursing with emphasis on physical care is pervasive and is apparent in the Report of the Committee in Nursing when it says patients receiving intensive care require 'constant, individual and skilled nursing' while those almost ready for discharge from hospital 'now need little or no nursing care'.⁽⁵⁹⁾

Maintaining this view of nursing is reinforced by rewards traditionally given nurses for ability to cope and ensuring that 'work' has been completed, routines carried out and knowing and enforcing rules.⁽⁶⁰⁾ Abdellah et al⁽⁶¹⁾ consider that nurses have to function under pressure to follow the rules and regulations set down by the hospital and devoting time to the instrumental care demands by doctors, leaves little time or attention for communicating with patients.

The fragmentation of nursing, keeping communication with patients as something distinct from 'work' or 'nursing care' is a reflection of how nursing is organised at ward level and in the classroom. Nursing is generally organised around a number of routines with patient care divided into a number of discrete tasks to be performed.⁽⁶²⁾ This reductionism is apparent also in nurse education where Abdel-Al⁽⁶³⁾ found teaching related primarily to procedures. The organisation of formal education and the organisation of nursing at ward level were found to mirror each other. Nurses viewed nursing as a series of procedures into which the complex issues of communicating with patients does not comfortably fit.

Organising work into a series of discrete tasks need not necessarily restrict verbal interaction between nurses and patients. When Goddard⁽⁶⁴⁾ pointed out how little time was spent in personal conversation with patients, nurses explained that it was unnecessary to spend time 'merely talking to patients' because one needs to do something for patients in order to encourage patients to talk and find out anything about them. The 'good nurse' would find the opportunity to do this during the course of 'ordinary nursing duties'. Nurses also reported to Stockwell⁽⁶⁵⁾ that the carrying out of ordinary nursing tasks provided adequate opportunity for interaction with patients. Duff and Hollingshead⁽⁶⁶⁾ and Wells⁽⁶⁷⁾ indeed showed that when verbal

interaction took place between nurses and patients it was likely to occur within some other, generally physically oriented activity, but the range of conversation was restricted and concentrated primarily on the treatment the nurse was performing. When time is available between tasks to be performed this is unlikely to be used in talking with patients. Goddard⁽⁶⁸⁾ found nurses used it to tidy cupboards or make stock. When staffing levels were increased with the expectation that greater time would be spent with patients, New et al.⁽⁶⁹⁾ found most nurses chose to engage in activities away from patients.

The division of labour on the ward determines which nurses will come into contact with patients most regularly, hence affording opportunities for formal or informal information giving. Ward sisters spend least time interacting with patients, especially in intimate situations.⁽⁷⁰⁾ Qualitative aspects of the interactions may be more important than quantitative and McGhee⁽⁷¹⁾ reports ward sisters having particular policies relating to deliberate efforts to engage in 'informal and personal contact' with patients compared with restricting interaction to formal encounters at ward rounds and the like. The characteristics of the ward in terms of the work to be done, the organisation of that work and how nurses perceive their work will determine to some extent whether, which, when and how nurses interact with patients. This in turn will influence the opportunities, at least potentially available, for communication.

Relationships with medical staff and communication with patients

The relevance of the relationship between nurses and doctors to communication between nurses and patients is demonstrated in the following quotation from Revans:

'...if the consultants appreciate the suggestions of the ward sisters, or even seek them, the ward sisters will be anxious to have ready for those consultants the maximum information about the patients. To get this information the ward sisters will encourage their nurses to discuss the patients with them. This, in turn, means that the nurses will tend to communicate more with the patients, and this communication will encourage the patients also to ask questions. If, on the other hand, the consultants do not regard their ward sisters as important sources of information or advice about the patients, the ward sisters in turn will have little cause for encouraging the nurses to discuss and report on the patients in detail. The nurses therefore, will not be motivated to observe patients closely.' (72, p.4)

Although the doctors regard for the ward sister may influence the kind of information she passes on to him, the social distance between doctors and nurses has been recognised as an inhibiting factor in the development of collegiate relationships.⁽⁷³⁾ In situations where status differentials are minimised it has been demonstrated that lines of communication between doctors and nurses are more flexible and interaction across occupational boundaries more developed.^(74,75)

Although 'team' conferences have been advocated as a means of improving interdisciplinary communication, 'team' characteristics do not necessarily exist⁽⁷⁶⁾ and in practice doctors are dominant with the senior doctor likely to exert most pressure and have his decisions carried.^(77,78) In surgical wards where such conferences were arranged for the specific purpose of exploring and reducing ward problems, and particularly those associated with cancer patients, nurses remained inhibited in their contributions.⁽⁷⁹⁾ McIntosh⁽⁸⁰⁾ found that the consultant's jurisdiction over telling was absolute.

Brown⁽⁸¹⁾ characterises the nurse-doctor relationship as the doctors giving orders and directing action. This is reflected in a failure to initiate and exchange information with nurses about the welfare of patients and nurses' inability to insist on such discussions.

Although doctors apparently assert total responsibility for decision taking regarding what is communicated about diagnosis and prognosis, even apparently rigid rules are not immutable. Strauss et al.⁽⁸²⁾ have observed the negotiated characteristics of much of what takes place in hospital with revision necessary because the special circumstances of specific cases makes universal prescription of informal rules impossible.

With regard to information other than diagnosis and prognosis, there is far less clear cut delineation of responsibility between doctors and nurses. Kutner, therefore, considered

'the unresponsiveness of some nurses to some of the unmet social and psychological needs of patients may be understood, therefore, as not stemming from ignorance of these needs or a lack of desire to care for them, but from a fundamental disagreement or lack of concurrence as to the areas of professional responsibility legitimately to be covered by physician and/or nurse.' (83, p.396)

These 'unaccountable' areas, as they have been described by Strauss et al.⁽⁸⁴⁾ constitute invisible action, that is, it is not deemed necessary to report back to superiors.

These factors of status differential, role ambiguity, and unaccountable actions contribute to the generalised finding that communication between doctors and nurses is limited in quantity and is confined to circumscribed aspects of patient care. Georgopoulos and Mann⁽⁸⁵⁾ found nurses sought only information about patients which would enable them to complete medical orders. Those nurses who have most contact with patients are least likely to have opportunities for direct conversation with doctors and such conversation as does exist avoids touching on how the patient feels about his illness or the management of communication with him.⁽⁸⁶⁾ Quint⁽⁸⁷⁾ found that nurses did not routinely ask doctors for information about the extent of the patients' cancer. This made it easier to respond that she did not know and tell the patient to ask the doctor.

Nurses are at times hindered in what they know about patients by a purposive or unintentional withholding of information by doctors. Information about patients entering the 'nothing more to do phase' of terminal illness was withheld from nurses; in situations characterised by uncertainty doctors talked in oblique terminology.⁽⁸⁸⁾ Technical jargon may be used so that nurses miss the finer points and different semantic interpretations increase the problems of establishing workable communication related to patient care.^(89,90)

It is the ward sister of all nurses who is most regularly stated by patients as a source of information.⁽⁹¹⁾ This relates partly to the ward sister or her deputy being most likely to come into contact with medical staff, be present on ward rounds and hence most likely recipient of details of the patient's medical condition and what transpires between doctor and patient. Mauksch⁽⁹²⁾ however showed that less than 15 per cent of staff nurses were aware of physicians' communications with patients.

In attempting to understand the nature of communication between nurses and cancer patients, it seems important to consider how nurses relate to and communicate with medical staff. Questions are also raised about the extent of the consultants' authority regarding telling, the nature of rules and whether situations arise in which nurses negotiate disclosure or disclose against the rules. However, in view of the findings that what patients know about their illness is not necessarily related to what the doctor said,⁽⁹³⁾ that patients' awareness is likely to oscillate over time⁽⁹⁴⁾ and what the doctor considers he has told is not necessarily the message received,⁽⁹⁵⁾ it would be misleading to lay too much stress on nurses' complaints that their interactional difficulties stem from not knowing precisely what the doctor has told the patient.⁽⁹⁶⁾

Communication between nurses

Senescu writes:

'It is difficult to imagine how satisfactory communication can be established, let alone maintained, with a seriously ill patient unless communication and co-operation among the staff or team is of a fairly high order'. (97, p.696-697)

The hierarchical ordering of nursing has implications for communication, Wessen⁽⁹⁸⁾ found interaction typically followed status lines and was inhibited by status boundaries. The infrequency of communication between ward sister and student nurse has been reported as well as a direct relationship between the frequency of informal communication between ward sister and other grades of nurse.⁽⁹⁹⁾ Katz⁽¹⁰⁰⁾ reports nurses withholding information from untrained ward staff, thus controlling access to information about patients.

Blau and Scott write that

'hierarchical dependence blocks the free flow of communications and, more specifically disinclines staff members to discuss their problems with a superior for fear of revealing their ignorance to him'. (101, p.131-132)

Observation of nurses' ward report sessions indicates that these are primarily one way communications with sisters passing instructions to nurses. When nurses volunteered observations they received negative responses.⁽¹⁰²⁾ Walker noted that untrained staff listened to exchanges between registered nurses rather than participating.⁽¹⁰³⁾ When efforts were made to use a 'team' approach to working with cancer patients, however, Shepardson⁽¹⁰⁴⁾ noted that some of the best insights about patients had come from auxiliary personnel who spend most time with the patient.

Mauksch writes:

'In the performance of her co-ordinating function the nurse, like workers in other pursuits, is prone to perform, first, those tasks which are subject to recording and reporting.' (105, p.128)

This partially explains the finding that much of what is communicated between nurses at shift reports relates to physical care, the collection of specimens or physiological data.⁽¹⁰⁶⁻¹⁰⁸⁾ Ross reports that only 5 per cent of shift report information related to patients' psychosocial characteristics⁽¹⁰⁹⁾ and Walker found similarly low levels.⁽¹¹⁰⁾

Written communications between nurses are regularly described as imprecise and characterised by omissions rather than inaccuracies, omissions which Georgopoulos and Jackson identified as being primarily in 'nurse dependent areas of care'.⁽¹¹¹⁾ Differences between wards have been identified however with nurses' notes in medical wards reflecting more importance attached to patients' non-physical needs than in surgical wards. Overall however notes were little used and what was recorded were considered by nurses as 'pertinent facts'.⁽¹¹²⁾

Payne and Krant⁽¹¹³⁾ found that what cancer patients had been told about their illness was not recorded in their notes and when this information is specifically asked for, it was not unusual for the response to be 'nothing'.⁽¹¹⁴⁾ When the management of individual patients presented problems for nurses, Glaser and Strauss⁽¹¹⁵⁾ noted that at times ad hoc accountability for communication acts arose and staff together organised action. This was the exception, however, and discussion about non-troublesome dying patients was typically absent.⁽¹¹⁶⁾

Despite the apparent insignificance of nurses' communications with patients as reflected both quantitatively and qualitatively in their communications with each other, for terminal patients Glaser and Strauss report that it was nurses who had to bear the brunt of managing patients' awareness of dying.⁽¹¹⁷⁾ Mauksch⁽¹¹⁸⁾ also points out that it falls to nurses to bear the brunt of what he calls the 'ministering' function of the hospital. McIntosh⁽¹¹⁹⁾ on the other hand, found that nurses were rarely asked by cancer patients about their diagnosis or prognosis

either by direct or indirect questions. How do patients ask nurses and how to they respond? How much of a problem is the management of patients' awareness? Whether nurses among themselves discussed their communications with patients and how patients responded to their illness and what they had been told were examined in the present study.

Ideology

While the literature suggests that nurses would be unlikely to disclose patients' diagnosis or prognosis, and pointed to some organisational and structural factors influencing this, the decisive factor determining nurses' communication practices was likely to be the prevalent ideology of medical staff. Strauss et al. write:

'Ideologies provide frameworks for judging both how patients should be helped and what is harmful for patients. Those judgments have moral overtones.'
(120, p.361)

Thus what nurses think of the effects of giving or withholding information from cancer patients will contain judgments as to the right or wrong of so doing from moral, ethical and humanitarian standpoints. Roberts⁽¹²²⁾ demonstrates this when she writes that her action of bluffing her way out of a patient's question as to whether she had cancer '...was ethically the only thing I could do'.

The extent to which an individual adheres to a particular ideology will influence behaviour, including their treatment of patients. In studies of psychiatric nurses, however, Strauss et al.⁽¹²³⁾ found that nurses tended to comply with the treatment directives of the physicians with whom they worked rather than nursing according to their own ideological stance. Altschul⁽¹²⁴⁾ found no evidence for psychiatric nurses holding particular treatment ideologies. Towell⁽¹²⁵⁾ noted that while an 'official ideology' of therapeutic community existed,

the ideologically derived prescriptions for actions sometimes contrasted with or conflicted with the requirements of the larger organisation. The latter was structured along traditional lines of status role differentiation and authority with associated expectations of behaviour. An understanding of nurses' behaviour therefore involved a consideration of both 'official ideology' and 'formal system'.

McIntosh found that nurses adhered to the dominant medical ideology that

'Patients were to be given as much information as possible about their condition and treatment short of divulging the precise nature of their illness and consistent with the retention of hope.' (126, p.28)

Roberts also asserted that the content of her communication with cancer patients complied with medical directives:

'The need to lie is not my decision. I simply do as I am asked by the doctors...' (127)

Explanation of nurses' communication with patients therefore requires not only consideration of whether nurses demonstrate ideologies on telling but also whether medical staff exhibit ideologies and the extent to which these are shared and made explicit. Prescriptions for action grounded in ideology may conflict with rules about nurses' perception of their role vis a vis communication. The interrelationship of ideology with other constraining and influential determinants of nurses' communication required consideration.

Nurses' Values and Beliefs about Telling

Ideologies derive from socially conditioned value and belief systems. How nurses communicate will therefore derive from beliefs held about their role and status as well as beliefs and assumptions about cancer patients, their desire for information and the effects of information.

The paucity of verified knowledge regarding communication of information to cancer patients, and about processes of nurse-patient communication generally, have led to an area in which few nursing directives exist.

Quint writes:

'The rules governing conversation with patients are less explicit than the rules governing physical care and technical procedures generally speaking the management of conversation is left to the common sense determination of the nurse.' (128, p.79)

Although knowledge exists which demonstrates that information and the reduction of uncertainty reduces rather than increases anxiety in many situations, ⁽¹²⁹⁾ this knowledge is not necessarily incorporated into the nurses' belief system about the effects of giving cancer patients information. Indeed the opposite is generally held to pertain, that to inform patients that they have cancer will create or increase fears and anxieties. ⁽¹³⁰⁾ Quint ⁽¹³¹⁾ found that tactics evolved to govern the amount of information given to cancer patients with the belief that this would foster the idea of recovery and maintenance of hope in the face of uncertainty and denies the reality of death.

In an attempt to develop a programme of milieu management for adolescents with leukaemia, it was advocated that the best way to help them and free them to talk about anything was to answer questions truthfully. Vernick and Lunceford found, however, among the nurses involved

'the general attitude expressed verbally and non-verbally was "the less these problems are discussed, the less upset the children will be".' (132, p.560)

Skipper writes:

'If nurses and physicians firmly believe that information will cause the patient undue anxiety and fear, they are quite likely to take the patients' signs of fear and anxiety over not knowing the nature and the state of his illness as "proof positive" that the patient's condition is such that he should not be told. This may become a self perpetuating process: the more that a patient worries about not being told, the more reluctant the personnel will be to tell him anything.' (133, p.79)

Hohloch and Coulson report that although student nurses were aware of cancer patients' needs to talk about their illness and associated feelings, they avoided exploration of topics which they believed might lead to further doubt and possible despondency.

'Rather than lead the patients into conversations which might be threatening to the patients or themselves and their convictions, the students chose to avoid such conversations.' (134, p.10)

Reiter and Kakosh⁽¹³⁵⁾ found this same avoidance of issues like the results of biopsy, diagnostic tests and diagnosis with cancer patients. McIntosh⁽¹³⁶⁾ found nurses giving reasons for not telling included beliefs that patients did not want to know, telling would evoke a bad reaction, patients would become hysterical as well as fear that telling would disrupt the ward atmosphere and create greater interactional difficulties.

Despite this, general reluctance to disclose diagnosis or prognosis, Glaser and Strauss^(137,138) found nurses giving information about their condition to dying patients when they believed that by doing so they would allow patients to make an adequate parting from their families or when they feared that to continue to deny to patients that they were dying, they would lose their trust.

Most commonly, however, beliefs associated with informing cancer patients are associated with fears that the patient will 'go to pieces',⁽¹³⁹⁾ of high levels of suicide⁽¹⁴⁰⁾ and the creation of unnecessary depression and worry among patients.⁽¹⁴¹⁾

Such beliefs stem largely from the anticipation of a single, permanent impact on the patient rather than an appreciation of processes and coping mechanisms likely to be employed over time,⁽¹⁴²⁾ they also derive from an earnest belief that it is kinder and less alarming to patients if cancer is not mentioned.⁽¹⁴³⁾ That patients do not ask adds further to the belief that they do not wish to know.⁽¹⁴⁴⁾

Contextual Variables

The importance of contextual variables in determining the content and structure of communications has been highlighted by Glaser and Strauss⁽¹⁴⁵⁾ in their studies of dying. They found awareness contexts, to be powerful, explanatory variables of communication between dying patients and hospital staff. Different awareness contexts produced different interactional problems.

As Hinton⁽¹⁴⁶⁾ has pointed out, it is difficult to measure the accuracy of one's perception of another person's awareness of the nature of their illness. This is especially so since awareness is not an all or nothing affair and represents a process over time with fluctuations in expression of awareness between different awareness states. Dickinson⁽¹⁴⁷⁾ found that it was this uncertainty about the patient's state of knowledge rather than whether the patient was known to be aware or unaware of his cancer and its prognosis which influenced nurses' sense of adequacy in communicating with patients. Not only uncertainty about how much the patient knows, but also about how much the patient wants to know and will admit to knowing will exist. This uncertainty is important if nurses stress the 'individuality' of care to patients, planning and giving care according to individual needs.⁽¹⁴⁸⁾ Although nurses' uncertainty about patients' knowledge or desire for information may be important in decision making, uncertainty has been found in other settings to be a factor creating restriction of information.

When real uncertainty about clinical matters exists, then Davis⁽¹⁴⁹⁾ observed a restriction of information to parents of children with polio and Roth^(150,151) found that information about the probable time scale of tuberculosis was withheld. This permitted staff manoeuvrability and avoided having to revise plans. This behaviour was generated by doctors and concurred in by nurses. With cancer, real uncertainty over clinical matters, initially about diagnosis and then about prognosis, is characteristic and is therefore likely to influence the control of information.

Davis however observed that when real or clinical uncertainty no longer existed, staff continued to project uncertainty into the situation. They used uncertainty to serve managerial functions in interactions with the polio childrens' parents. He labelled this as 'functional uncertainty'.⁽¹⁵²⁾ Uncertainty was therefore imputed in order to limit the amount of information disclosed. Quint⁽¹⁵³⁾ found this to happen in her study of mastectomy patients. She regarded the rationale behind not establishing certainty regarding cancer was to enable patients to maintain hope and avoid considering that death could be the outcome. McIntosh⁽¹⁵⁴⁾ came to the same conclusion with the added refinement that while attempts were made to maintain uncertainty about a cancer diagnosis, the opposite held for prognosis. Efforts were made to convey certainty to patients that the illness would have a favourable outcome irrespective of the clinical facts. An equally persuasive explanation for not divulging diagnosis and a poor prognosis is that no one likes to break bad news.⁽¹⁵⁵⁾ The role of the bearer of bad news has never been a comfortable one and so it is avoided.

Thus while uncertainties are likely to exist at times about some aspects of the illness and about what patients want to know or how

they will respond to knowing, invoking uncertainty in the management of communications is likely to be important. Other studies have shown that when faced with uncertainties routinized procedures develop⁽¹⁵⁶⁾ and that these are likely to be based on typifications of patients with particular conditions. In studying cancer patients with a variety of conditions and undergoing different treatments, this raises the question of whether communications would be associated with patient typifications. McIntosh⁽¹⁵⁷⁾ suggests that this is the case.

Other Factors Influencing Nurse-Patient Communication

Individual characteristics of nurses also play a part. Perucci⁽¹⁵⁹⁾ found that nurses who perceived less social distance between themselves and doctors and the greater the services they had with which to bargain felt less tied to formal rules. Hence they will feel less governed by traditional distinctions about who should give information. Dodge⁽¹⁶⁰⁾ constructed a personality dimension labelled 'psychological strength' and found nurses who perceived themselves as psychologically stronger were more likely to express the belief that patients should be kept informed than those who consider themselves 'psychologically weak'.

Some nurses were found by Glaser and Strauss to feel so frustrated and distraught in a closed awareness context that they would break the rules and inform the patient that he was dying. Particular nurses were noted for their abilities to discuss death.⁽¹⁶¹⁾ Quint⁽¹⁶²⁾ also reported that the one nurse observed openly confronting a mastectomy patient with the knowledge of her cancer had had personal experience of a sister who had undergone similar surgery.

These findings indicate individual differences in ability to communicate and are associated with features of personality and experience of the illness, rather than organisation. Though individual differences

in practice may exist, it is doubtful that a nurse could markedly deviate from the normative practices of a particular ward without experiencing negative sanctions. The relative privacy of nurses' encounters with patients however may protect her to some extent from being observed by others.

It was with such relatively private encounters that this study was concerned. It focussed on the interactional nature of nurse-patient communications as well as their processual features, thus considering nurse-patient communication as a dynamic rather than a static phenomenon.

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CHAPTER 2

PATIENTS AND THEIR FAMILIES

As with hospital staff, a number of interpersonal, intrapersonal and structural variables influence the communications engaged in by cancer patients and their families and the information they receive. Although it is conceivable to consider patients and their families together as the unit of nursing care, in terms of literature associated with communication about illness, patients and their families are regularly treated as distinct units. Lamerton, for instance, writes:

'In Britain today the patient is frequently told nothing about his diagnosis - he may even be told lies - yet his closest relatives are nearly always told.' (1, p.20)

Patients' Desire for Information

Evidence is well documented that a leading cause of dissatisfaction with care among patients discharged from hospital is lack of information,⁽²⁻⁴⁾ particularly information about their illness. Yet Dodge⁽⁵⁾ found patients ranked information about their condition as most important. These were not studies of cancer patients however, and, given the connotations of the illness, desire for information may vary with diagnosis.

The evidence on this matter depends on the methods of study and patient samples. Patients who do not have cancer overwhelmingly state that they would wish to know if they did⁽⁶⁾ and the large majority of cancer patients informed of their diagnosis agree with this practice.⁽⁷⁻⁹⁾ The picture is different for patients with diagnosed but undisclosed malignancy however. McIntosh⁽¹⁰⁾ found that only one third of cancer patients who suspected their diagnosis on admission to hospital would have liked it confirmed. When those who already knew that they had cancer were included, then about half of the patients wanted to know.

When prognosis was in question however, eighty-six per cent did not want to be told. This suggests that when patients are actually confronted with the illness and are uncertain about either diagnosis or prognosis, they are less inclined to want to find out.

The Availability of Information

The question of what constitutes information is a complex one. Hinton⁽¹¹⁾ for instance, reports that when patients discuss conversations they have had, often more than one message has been transmitted. Others have written that:

'Many patients hear only what they want to hear and then protest that they have not been warned about qualifications and complications'. (12, p.70)

Even though a diagnosis of cancer has been formally imparted, a proportion of patients cannot recall or report being told.^(13,14) Moses and Cividali⁽¹⁵⁾ found levels of awareness regarding cancer unrelated to whether diagnosis had been formally imparted and the literature is full of references to patients knowledgeable of their condition who have not been informed formally and others who deny all knowledge though confronted with the facts.⁽¹⁶⁻²⁰⁾ Weisman concludes:

'...there is no reliable method to determine what is actually told to patients and how much is assimilated.' (21, p.85)

Thus, even for formally communicated information, interpretation and assimilation is variable. Some explanatory factors lie in the use of different linguistic codes between layman and professional^(22,23) with different meanings attributed to medical terms.⁽²⁴⁻²⁶⁾ The choice of words used need not provide a meaningful explanation since labels for cancer commonly include lumps, bumps, abnormal tissues, new growths, tumour, neoplasm, mass^(27,28) or words like ulcer, inflammation,

polyps. (29, p.385) At other times the use of technical jargon makes the message incomprehensible. McIntosh⁽³⁰⁾ has found that the meaning associated with the various euphemisms used for a cancer diagnosis depends on the interpretation of the illness the patient is attempting to construct or maintain. Thus motivational and sociolinguistic factors interact. Influencing patients' desire for, perception and interpretation of information will be factors like the patients' psychological status and style of adaptation to illness.⁽³¹⁾ Does the patient want to know or avoid knowing? What influences such coping styles and thus communication? The meaning that cancer holds will be one factor.

Bard writes:

'Anxiety present in every cancer patient is a formidable barrier between him and those around him. It causes distortions, shifts in emphasis, indeed inability to comprehend, to remember, even to hear.' (32, p.109)

A related phenomenon is the patient's level of uncertainty about his condition. Maslow⁽³³⁾ identifies a general drive to reduce uncertainty and the anxiety which uncertainty typically generates. He suggests a dialectic exists which is simultaneously a struggle between fear of knowing and courage to know. All the psychological and social factors which increase fear will cut the impulse to know while those permitting freedom and boldness will encourage the need to know and hence the search and receptivity for information. With an illness like cancer, this dialectic is undoubtedly prevalent, but how does it reveal itself in the process of communication? What factors influence information seeking?

Availability of information will also be influenced by factors like whether patients are prepared to ask. Apart from not asking

because they have no wish to know, other factors interfering with asking include diffidence⁽³⁴⁾, perceived social distance,⁽³⁵⁾ avoiding the possibility of negative sanctions^(36,37) and attempts to avoid embarrassment or create an uncomfortable atmosphere with staff.⁽³⁸⁾ Of course patients' asking will relate to the strategies of information management employed by staff.^(39,40)

Who the patient asks will also influence what he hears. Weisman⁽⁴¹⁾ found that patients would ask about diagnosis and prognosis and speak of deeper concerns but only to someone not in authority. By relying on those of little personal significance this was seen to avoid the risk of rupturing significant relationships. Parkes⁽⁴²⁾ attributes patients' asking nurses questions they would not ask doctors to the fact that they could more readily disbelieve the nurse if she told facts about the illness they were not ready to know. It is Hinton's observation that patients seek to meet different needs through different people:

'perhaps demanding optimistic reassurance from one source and yet welcoming a realistic and sombre exchange of words with another.' (43, p.111)

Thus whether the patient asks and the source of information as it relates to its authority and significance for the patient will further influence the availability and interpretation of information.

Sources of Information

Formal communication between patients and hospital staff is the most readily recognisable source of information for patients. Whether a nurse is asked will depend on the patient's perception of her role related to information giving and her credibility. Frame⁽⁴⁴⁾ asked patients who they would ask for details of their condition and 38 per cent said that they would ask a nurse, especially a senior nurse. Skipper, however, observed that patients tended not to ask nurses

because past experience had taught that they would receive unsatisfactory answers and led to the belief that nurses did not have the authority to pass on this kind of information.⁽⁴⁵⁾ Peck⁽⁴⁶⁾ found only 2 of 50 cancer patients asked a nurse or radiographer about their diagnosis.

Formal communication however is by no means the only or perhaps even the most important source. Many patients know their diagnosis and prognosis without ever having been explicitly told.⁽⁴⁷⁻⁵⁰⁾ Hospital staff can convey information by their descriptions of the illness without mentioning the words cancer or malignancy⁽⁵¹⁾ and non-verbal behaviour contains much information for the alert patient.^(52,53) Quint⁽⁵⁴⁾ reports that mastectomy patients were extremely sensitive to the behaviour of others, especially those in whom they had a vested interest. Gerle et al. report a patient who said on discharge from hospital:

'I could see from the doctor's face that I had cancer. Why did everyone's attitude change though they told me the operation did not disclose anything alarming.' (55, p.1210)

Although the content of speech and behaviour are important, also perceived by cancer patients as meaningful is what is left unsaid. Weisman⁽⁵⁶⁾ reports cancer patients as being alert for what is not said and Renneker and Cutler⁽⁵⁷⁾ found that not to speak of cancer was interpreted as signifying a fatal outcome.

'If a patient is not told what is wrong with him, he not unnaturally assumes the worst.' (58, p.23)

It is not only hospital staff who provide information but the patient's own family and other patients. Verwordt says that no matter what relatives are told this will be, in some way, transmitted to patients.⁽⁵⁹⁾ Parkes comments on the difficulties of relatives keeping information from patients:

'It is, of course, very difficult for a woman who has been in the habit of sharing her thoughts and anxieties with her husband to mislead him...' (60, p.64)

Thus, while relatives may unintentionally convey information, the evidence strongly supports that they are just as likely as staff not to want to tell patients. As Hinton writes:

'It is not only doctors who are reluctant to communicate with cancer patients, relatives and friends often believe it is wrong for the patient to be told. They will join vigorously in the collusion to deny anything but hope.' (61, p.111)

Why do relatives behave in this way? How do they manage communication? Are they a source of information for patients?

Other patients are a more likely and well recognised source of information in a variety of situations. (62-65) Glaser and Strauss however report a nurse's observation that among cancer patients the rules of tact were so strong that patients rarely conversed about anyone's condition. (66) Recently McIntosh found cancer patients conversing meaningfully about their condition without using the word cancer. (67)

In other studies patients were observed to form groups in an attempt to resolve stress and work out solutions to their problems. (68) Caudill (69) and Smith et al. (70) describing psychiatric patients, attribute group formation to the absence of communication between patients and staff. McIntosh (71) attributes it more to the greater control patients have over information obtained in this way. In the present study communication between patients was examined in an attempt to identify its function and the relationship between communication in formal as compared with the informal network.

Cues are available by the very fact of being in hospital. Roth writes of the tuberculosis patient that he:

'...never stops searching for clues that may help him guess what stage of the treatment process he has reached and how much longer it will take.' (72, p.xvi)

As well as the label of the ward, information is also provided in the

types of medical investigations and treatments experienced.^(73,74) Biopsy and radiotherapy are particularly strong cues⁽⁷⁵⁾ while mastectomy is regularly perceived as indicating breast cancer.⁽⁷⁶⁾ The patient's own symptoms additionally provide some indication of the state of the illness⁽⁷⁷⁾ especially in cancer when the disease is known to spread. The patient may also learn something about his condition from reading his case notes, or eavesdropping on conversations.⁽⁷⁸⁾ Thus the potential in the informal communication network seems enormous. To what extent do patients rely upon it rather than information formally available?

The Acquisition of Information

While information about their illness may be potentially available, how do patients actually acquire it? Some factors related to propensity to asking have been examined but environmental variables, like degree of privacy⁽⁷⁹⁾ or whether opportunities are available for close personal attention,⁽⁸⁰⁾ will influence the kind of opportunities available to patients.

The evidence indicates that regularly patients wishing to learn about their condition are not offered all of the information they want and the onus is on them to ask.^(81,82) The patient may have to learn not only what to ask⁽⁸³⁾ but how to ask the appropriate questions⁽⁸⁴⁾ as well as who to ask, since not all personnel will interpret questions and answers in the same way.⁽⁸⁵⁾ This may then entail a process of asking different personnel the same question and making a comparison of the answers.⁽⁸⁶⁾ Alternatively, if it has already been ascertained that staff are unlikely to answer questions, patients will rely on the informal social network to share observations and information about staff in order to decide who is most likely to be forthcoming and ask them whenever possible.⁽⁸⁷⁾

Asking directly does not mean that the patient will receive the desired information and he may be forced into a bargaining position. Roth⁽⁸⁸⁾ described how tuberculosis patients used standard bargaining techniques like appealing to established norms, applying pressures in the form of a barrage of questions and enlisting the aid of an intermediary. He also suggested more covert techniques were engaged in by attempting to assess the outcomes of certain behaviours on others and altering behaviours to project a desirable image.⁽⁸⁹⁾ Glaser and Strauss⁽⁹⁰⁾ described that the agreed outcome in negotiation for information about dying depended on the extent of norm sharing between participants.

As in any bargaining situation the relative power of the participants is an important feature. Patients are not devoid of all power and Roth found tuberculosis patients could threaten to discharge themselves⁽⁹¹⁾ and otherwise act irresponsibly to convince the authorities of the sincerity of their threats.⁽⁹²⁾ Cancer patients may also threaten to discontinue treatment or withhold co-operation⁽⁹³⁾ but since the illness is not communicable, then their bargaining strength is likely to be less powerful than that of tuberculosis patients. Also with the threat of litigation less prevalent here than in the United States, the bargaining position of patients is considerably reduced compared with their American counterparts.

Stockwell⁽⁹⁴⁾ observed that when nurses refused to take a patient's expressions of anxiety seriously, the patient took the initiative in arranging that his wife discuss his problems with the consultant on his behalf, an action repeated by other patients. Is it possible for cancer patients to use an intermediary?

The foregoing discussion shows the kind of questions related to patients which the study examined. Its other aspect was to consider

how cancer was affecting patients' families and their communication with hospital staff.

The Families of Patients

Not a great deal is known of the details of communication with the families of cancer patients. It is generally known that the family is better informed than is the patient himself. Cartwright et al.⁽⁹⁵⁾ reported that 88 per cent of caring relatives knew the diagnosis of patients who died of malignant disease. As well as being more likely to know diagnosis Quint⁽⁹⁶⁾ found that the family were more likely to be given fuller, more detailed information about other aspects of the illness than were mastectomy patients themselves.

Although relatives on the whole appear more informed than patients, Cartwright et al. found a quarter of all relatives who had cared for patients who had subsequently died were not given as much information as they would have liked about the illness. Five per cent would have liked something explained in more detail and a further four per cent were not able to find out about things as soon as they wanted.⁽⁹⁷⁾ Hampe,⁽⁹⁸⁾ interviewing spouses of terminally ill patients, also discovered that although they all expected information regarding the patient's diagnoses, treatment and complications of the illness, less than half had these needs met in full and for four of twenty-seven spouses, not at all. Less than half of the spouses expressing a need to learn of the patient's day to day condition had this met and more than half felt that neither they, nor the patient, had received emotional support. Which relatives are informed and which are not may be influenced by factors like age, perceived mental stability and intelligence.⁽⁹⁹⁾

The situation regarding disclosing the condition of dying patients is not necessarily similar to non-terminal disease and both Parkes⁽¹⁰⁰⁾

and Hampe⁽¹⁰¹⁾ consider greater pressure on the doctor to impart information when the illness will prove fatal. The family will learn in any case and, if uninformed, may then blame the doctor for misleading them. McIntosh⁽¹⁰²⁾ found this difference between the likelihood of volunteering information about prognosis to the relatives of terminally ill cancer patients and imparting a diagnosis to others.

Wives of patients who had survived myocardial infarction were found to lack specific information regarding the illness and therapy^(103,104) suggesting that although diagnosis and impending death may be imparted to relatives, they are less likely to have details of treatment and other aspects of the disease. As with patients, the information ostensibly given relatives is not necessarily the same as they are able to recall. Of particular significance is that relatives of patients in hospital are likely to be broken the news of a potentially fatal illness by a strange doctor at a single interview.⁽¹⁰⁵⁾ Harrisson describes that when information of a high emotional content is passed on:

'...it is common to find a cut off point operates allowing only a limited amount of information to be absorbed; thus effectively curtailing potential information.' (106, p.66)

While relatives consistently are found to be better informed than patients, McIntosh⁽¹⁰⁷⁾ found that the onus was firmly on relatives to initiate enquiries.

Barnes wrote:

'Finding out how the patient is getting on seems to be as difficult for the relatives as for the patient himself ... any guilt feelings they may have about sending him to hospital are sharpened by the seeming unapproachability of the staff. If they can overcome these feelings enough to seek out information, they still have to discover which members of staff to approach. The head nurse may be surrounded by questioning relatives and unable to deal with them all. Sometimes she cannot be found. The doctors usually avoid the ward at visiting times - a further indication, it was thought, of their need to be detached from such personal things as patients' families.' (108, p.118-119)

Cartwright et al. also reported that some relatives found it difficult to get information from the hospital, they did not know who to approach and those to whom they spoke were evasive. (108, p.174) While senior nurses were reported as a frequent source of information, no qualitative data is provided. Nurses were reported by only 4 per cent of respondents as breaking the news of the patient's diagnosis when death was due to a neoplasm compared with only 6 per cent for other diagnoses.

When nurses were approached McIntosh⁽¹¹⁰⁾ found them referring relatives to doctors and then engaging in bland statements. Davis found nurses dealing with the parents of polio children talked in 'generalities and evasions'⁽¹¹¹⁾ and Duff and Hollingshead⁽¹¹²⁾ also report nurses as concurring, in the 'fictions and evasions' circulated by doctors regarding the probable outcome of illness.

In the present study the frequency of contact between relatives and hospital staff was examined as well as the qualitative nature of communications. How much did relatives want to know? How did they attempt to find out? Why might some relatives not want to know?

Much of the available literature does not permit an understanding of the processes of communication and as such is of little help to nurses in understanding their own behaviour or that of colleagues, patients or their families. In reviewing the literature a number of questions were identified and answering them entailed collecting different types of data from different individuals. The methods used to obtain the necessary data are discussed in the following chapter.

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CHAPTER 3

METHODS

The questions and associated hypotheses deriving from personal experience and literature were regarded as tentative. Potential explanatory variables were indicated in the literature but the emergence of others was anticipated in the course of data collection and analysis. In examining the processes associated with communication, it was decided to adopt, at least in part, the grounded theory approach advocated by Glaser and Strauss.⁽¹⁾ As changes in focus occurred while the study progressed, this facilitated the emergence of new hypotheses and propositions. For instance, very early in the study an initial assumption that patients would attempt to reduce uncertainty regarding their diagnosis, if not their prognosis, was found to be untenable. This caused a revision of ideas associated with the power and complexity of uncertainty as an explanatory variable and a revised set of hypotheses regarding the management of uncertainty by both patients and staff.

The interrelated nature of the questions posed within the general problem area and the conceptualisation of communication from an interactionist perspective and as processual in nature merited an approach enabling the collection of first hand data over time and with enough flexibility to permit and maximise the discovery and verification of theoretical propositions. Participant observation was the obvious method and is defined by Denzin as:

'... a field strategy that simultaneously combines document analysis, respondent and informant interviewing, direct participation and observation and introspection.' (2, p.186).

Denzin further considers that:

'... participant observation may be most profitably treated as a method of qualitative analysis that requires observer submersion in the data and the use of analytic induction and theoretical sampling as the main strategies of analysis and discovery.' (p.186)

Method and analysis thus go hand in hand. Events in the ward were carefully observed and recorded but this was insufficient to provide data on, for instance, nurses' and doctors' views on communication with patients, patients' awareness of their illness and how this may change over time or relatives' desire for information.

Observation was therefore complemented by formal interviews and/or informal conversations with patients and their relatives, doctors, nurses and other categories of hospital staff. Some questionnaire data were also collected from relatives to ascertain frequency of contact with hospital staff. By using various methods of data collection, as well as being essential, each one also provided a check on the validity of data collected by the other methods.

Pilot Work

Never having used field methods, some practice prior to entry to the main research setting was deemed necessary. Some days were spent observing and interviewing in each of three surgical/gynaecological wards in April and May of 1972. There were a number of reasons for conducting this preliminary exercise, not least of which was to gain some confidence in working as a nurse researcher in a hospital environment. Although spending a few days in a ward would be very different from the prolonged observation in the main study, the situations would be similar enough to provide useful experience and Geer⁽³⁾ had alerted me to the importance of the beginnings of fieldwork. Valuable experience was gained in the selected wards in trying out different techniques of observation

and recording, in formal and informal interviewing, and using a tape recorder. It was also possible to make a start with abstracting categories from data.

Some problems were encountered in presenting my role and the study to both nurses and medical staff. It was evident that enthusiasm for the research topic and the researcher's presence was not shared by all staff members and some difficulty was experienced in observing all categories of relevant interaction. It was pointed out that my presence at interviews between doctors or nurses and relatives would have constituted a deviation from the normal practice of providing privacy and it was evident that some members of staff felt extremely uncomfortable being observed. As I tried to observe patterns of nurses' work from different vantage points one ward sister commented:

'You'd be far better off helping the nurses with the patients than sitting here spying on us. We feel like we are being spied on.'

On the same day however, a staff nurse commented:

'I hadn't even noticed you here today, we have been so busy rushing round.'

Participating in nursing duties was attempted and would certainly have yielded useful data, but it was anticipated that in the main study this would restrict mobility and the range of data available since nurses did not accompany patients away from the ward. Being closely identified with the nursing staff was also initially considered limiting in terms of being able to associate with other groups. Claiming a nursing identity on the other hand legitimised my presence to some extent. Patients said that they did not mind a nurse being present at examinations and ward rounds but they may have objected to a non-nurse. I therefore decided to tell patients that I was a nurse but not associated with the hospital. It was

also anticipated that not engaging in nursing duties would reduce some of the emotional difficulties described by Quint⁽⁴⁾ when research nurses adopted a participant nursing role. She stresses however that nurse fieldworkers invariably face problems in the perspective from which they view potential data. The role conflict of being both nurse and researcher was not fully appreciated until the main study.

Setting for the Study

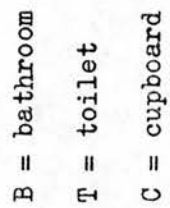
It was decided to conduct the study in a situation where there was a concentration of patients with malignant disease rather than where comparisons with non-malignant conditions could occur. The most suitable setting was a Department of Radiotherapy* where patients with malignant disease in its many forms and stages were treated.

This Department is situated within a District General Hospital, built initially as a Poor Law Institution in the middle of the last century. The Radiotherapy Department in contrast to the original building was modern and purpose built. There are two wards which are almost exact replicas of each other. Ward 2 has 52 beds and is situated directly over Ward 1 which has 58 beds. Figure 1 shows the general layout of Ward 1 indicating its spaciousness and the organisation of patients' rooms and common areas and showing the location of the nurses' station and duty room. The area occupied by the theatre and hostel rooms in Ward 1 were allocated to an

*Details of names and places have been altered and not systematically applied to protect identities. All doctors are referred to as male although both males and females were included. All nurses were female.



Layout of Ward 1



independent MRC Medical Unit in Ward 2 and only 2 beds, compared with 8 in the other ward, were available and accounts for the differential. The MRC Unit treats patients with a variety of non-malignant conditions and has the use of two or three beds in the ward at any time. Thus over 100 cancer patients are in the Department at any one time.

Below the wards are two floors housing offices, examination rooms, radiotherapy and diagnostic X-ray facilities and the Medical Physics Department.

The Department is a regional centre and treats patients from a wide catchment area. Although smaller treatment centres exist elsewhere, these have restricted treatment facilities and so patients with particular types of disease requiring more specialised treatment facilities are referred. As well as patients with a variety of malignant conditions at different stages currently undergoing radiotherapy and/or chemotherapy, the wards at various times were found to contain other types of patient. Included were cancer patients who had completed treatment and awaited transfer to another hospital or home, patients who had undergone surgery and were referred back to the Department, patients admitted on a regular basis for reassessment and patients in the terminal stages of illness. Patients admitted with non-malignant conditions included the MRC patients, those with ankylosing spondylitis being treated by radiotherapy and, more often, 'boarders' when beds were unavailable in more appropriate wards. A team of seven consultants served the Department. Each had a specialist interest but, because some served peripheral clinics and were responsible for treating all patients referred there, they were also generalists in terms of the malignant conditions treated. Associated with the consultants were registrars, some of whom were

studying for a post-registration qualification and were assigned to the different consultants in rota. To each ward a house officer was allocated. He was concerned with the day to day management of patients but minimally involved in the planning of chemotherapy or radiotherapy.

Each of the wards had permanent nursing staff of one ward sister and varying numbers of full-time and part-time trained nurses. Part-time nursing auxiliaries, many of whom had worked there for a considerable time, added stability and made an important contribution in terms of their organisational knowledge. Students and pupil nurses at all stages of training spent periods of up to two months gaining experience in the Department and were also an important part of the work force. At the time of the study only one staff nurse had a post-registration qualification in oncological nursing, but was present for only a few weeks and was not formally interviewed.

The third large group of staff were the radiographers comprising a superintendent with a team of trained staff and students, and one diagnostic radiographer. Only the superintendent radiographer came to the wards to discuss treatment with some new patients. The others saw patients on the treatment floors, appearing in the wards only when a porter was not available to accompany a patient.

A steady stream of other hospital and Departmental staff visited the wards. These included the secretaries who organised admissions, the porters who accompanied patients to treatment, tests and examinations, consultants from other departments, the medical social worker, dietician, physiotherapist, the hospital chaplain and his assistant, and the WVS and library services. Informal interviews were held with all of these.

Arrangements for patients' visitors were extremely flexible and visitors were to be found at any hour from mid-morning until about 8 p.m., although most came during mid-afternoon and evening. Patients were permitted to go out of the hospital once their daily treatment had been completed (the daily radiotherapy fraction or chemotherapy was always referred to as treatment), and to go home at weekends if their condition permitted.

During weekdays the wards were characterised by high levels of activity. Although the bustle of the wards was absent in the evenings these were not necessarily quiet times for nurses. In each ward, staff was reduced to three and occasionally four, including one trained nurse and one nursing auxiliary, who at times had to cope with several severely ill patients as well as servicing the remainder of the large number of patients. At weekends the wards were characteristically quiet when most of the patients who were well enough went home, leaving only those too ill to venture out or, rarely, those having treatment over the weekend, and the few who, for social reasons, or because of distance from home, elected to stay.

Gaining Entry and Presenting the Study

Since the idea for the study was my own I had to initiate the approach to the appropriate authorities to gain entry and conduct fieldwork. I considered that dual entry would be necessary through both nursing and medical authorities and approached both the Regional Nursing Officer and the senior doctor in Radiotherapy in the spring of 1972. After these initial interviews gaining entry via the medical and nursing portals differed.

At the preliminary interview with Doctor W., the senior doctor,

I outlined that I was generally interested in the problems of communication concerning patients in hospital. I assumed that problems associated with information regarding illness would be maximised among patients with cancer and, for this reason, I wanted to study communication in the Radiotherapy Department. From the beginning he showed interest in the project and suggested that I write a research proposal for his consideration. This was submitted in due course and a further meeting arranged to include my supervisor. The subject matter of the study he considered acceptable but methods were anticipated as presenting problems, particularly in obtaining 'objective' data and data from patients. The research proposal read:

'As well as informal talking and listening, it is proposed that patients may be interviewed on admission in order to gain some impressions of their knowledge of their illness, with less formal conversation at intervals during their period of hospitalisation.'

When the proposal was taken by Dr. W. to the next consultants' meeting, permission to carry out the study was obtained with the proviso that patients should not be interviewed.

With hindsight I realise that I could probably have received permission to formally interview patients once my presence had become more established. Schatzman and Strauss⁽⁵⁾ have written:

'any restrictions initially accepted by the researcher should be regarded as renegotiable at later, more propitious times.' (p.18)

The study would certainly have benefitted from more full data on subjective aspects of patients' response to their illness on admission. However I did not feel that I could make such demands.

Although the consultants had discussed the project, some had only a hazy idea of what I was trying to study. Comments ranged

from 'Oh you are doing this funny business' to 'Exactly what are you anyway?'. In an attempt to have myself and the study accepted, I found myself emphasising my social science academic background with medical staff and playing down the fact that I was a nurse, while the opposite prevailed among nurses. I had assumed the information would filter through the medical hierarchy but registrars and house officers had heard nothing of the study and so I gradually introduced myself, explained the study and asked permission to observe them with patients. Some medical staff expressed a desire to help and showed interest, some were passive and two did not wish to participate at all. I realised that a more formal presentation of the study might have been useful and subsequently presented a paper at the weekly Departmental seminar.

With nursing staff I was hoping to utilise an entry strategy which Khan and Mann⁽⁶⁾ call 'contingent acceptance at successive organisational levels'. I saw in turn the Regional Nursing Officer*, the Chief Nursing Officer, an assistant matron at the hospital concerned, and the ward sister of Ward 1, but the entry process did not go according to plan. I had proposed to canvas each level separately for permission to conduct the study but the message had been interpreted down the line that I would be doing the study and entry was settled. I was taken to meet the ward sister, who had been informed about the study by her superior at a most unpropitious time in the middle of a busy morning. We arranged that I would discuss the study later when I would meet some of the ward staff. The meeting with the ward nursing staff took place at the beginning of June 1972.

*At this time the nursing service was about to be reorganised within the 'Salmon' structure⁽⁷⁾. This took place while fieldwork was in progress, with a change in senior nursing personnel.

The study was presented to the nursing staff from the perspective of a number of questions concerning communication about cancer which were evident to me as a nurse - How much do patients know of their diagnosis or prognosis? What have they been told and by whom? How did they cope with their illness? How do nurses manage communication? How is information coordinated among staff? How can we explain and account for communication processes?

The selection of the Department was explained in terms of the benefits of being able to observe so many patients, nearly all of whom would have cancer. The nurses were invited to ask questions. They were interested in how I would do the study and assumed that I could not ask patients directly about their illness. They wanted to know whether I would do nursing and what I would wear. I explained that I would not actually do nursing because then I might get too involved, rather than trying to remain impartial, but that I would tell the patients that I was a nurse. I would wear a white coat so that I looked as if I belonged since lots of people in hospital wear white coats and I would wear a name badge which would also bear the label 'Nurse Researcher'. I explained that I was not too sure what kind of information I would collect but I would spend some time in the wards to see what was available and would not really begin the study proper for a while. Most of the time I would spend just watching what was going on and talking to people. The nurses were encouraged to come and discuss patients with me. The immediate response was 'You've certainly come to the right place. Our main problem here is lack of communication.'

The nurses had obviously discussed the study prior to my arrival and showed interest from the beginning. After the first afternoon one nurse asked 'Do you think it's going to work all right then?' I was also asked my own opinion about telling patients that

they had cancer to which I replied that this was a complex problem with no easy answers. I tried to stress that the purpose of the study was to describe systematically what happened to patients and their families since little was known even at this level, and not make judgements about what is right or what is wrong.

Nurses and doctors who arrived on the ward during the course of fieldwork were informed of my identity and my work as soon as an opportunity presented. At these times nurses not uncommonly rendered an account of some experience they had had or responded that what to say to patients was a problem they found vexing.

Later in the study it was necessary to renegotiate entry with the nursing staff due to errors of tactics and deportment of my part. This will be discussed later but points to the fact the entrée is a continuous process.

Beginning Data Collection

The month of June was spent gaining experience of the physical and organisational set up and gauging the availability of data. When and where particular kinds of interaction occurred, the routines associated with treatment of different patient categories and rhythms of activity were observed. At this time different observation techniques in different situations were attempted. I attended nurses report sessions in the mornings and afternoons, house officers' ward rounds, interviews between senior doctors and patients at review clinics off the ward, encounters between radio-graphers and patients and between patients themselves. What was said in each context was noted so that a picture of the processes being examined was gradually constructed.

In such a large ward it soon became evident that interactions between nurses and patients would be most difficult to observe

because so many things happened at once and because the physical layout restricted the visibility of nurses' activities. Observing relatives with patients was discounted for ethical reasons.

At this time informal conversations also took place with individuals in all subject groups. Patients, for instance, were asked about their treatment and progress, their perception of their illness and what they had been told about it. Informal discussion was necessary to clarify my perceptions of events and also to gain the perspective of others. These conversations were often prompted by some observed or reported event relevant to the testing of a specific hypothesis.

At this time I also had to come to some decision about how to present the study to patients. Clearly the same explicitness of explanation as that given staff was inappropriate although patients had a right to be given some account of the reason for my presence and their cooperation sought. Initially an explanation in terms of studying the organisation and coordination of patient care was given. After a patient suggested 'you would be far better to study communications', the study was in fact presented as being concerned with 'communication in hospital'. Patients' permission was sought to observe them when they were with doctors and nurses and to come and talk to them during their stay in hospital. No patient refused to co-operate while many said that they would be only too pleased to assist in any way possible. A few subsequently asked for more information about myself and the study but there was no indication of suspicion that I was interested in cancer or that my enquiries about their illness were out of place.

This period of preliminary fieldwork was aimed at serving another function, namely getting staff used to being observed. Fox writes:

'My own experience with direct observation in nursing has convinced me that while distortion is inevitably introduced, it does not persist for long periods of time. Therefore if direct observation begins with a period for acclimatisation and orientation when no data are collected, in most instances the research situation reverts to normal.' (8, p.202)

It was hoped that the present study would prove no exception. A programme for the study was then planned in an attempt to optimise the various sources of available data.

Observation Techniques

The kind of observation engaged in depends ultimately on the role adopted by the investigator. Using Gold's⁽⁹⁾ analysis, roles adopted varied in different settings, with different groups and over time but was generally within the participant as observer category. Dean et al,⁽¹⁰⁾ describe fieldwork as progressing from passive observation through participating in group activities to interviewing and the present study followed a similar course.

Interactions between nurses and patients presented a number of observational problems. Not least was being able to hear what was happening. To have been close enough to overhear what was said at all times in the ward would have been too disruptive. Tape recording would not have been tolerated. Several alternatives presented themselves but it was considered more fruitful to concentrate on the careers of particular patients rather than the sequential activities of particular nurses. The former could be supplemented by observations of nurses at work with other patients. The decision to focus on patients was influenced not only by the spatial and organisational characteristics of the wards but by the fact that I was interested in the processes of communication and each patient would experience this situation only once. The nature of nurses'

interactions with patients were such that they would be repetitive and something missed with one patient would be likely to occur again.

I finally decided to station myself in a room of four patients so that I could hear what was going on from a vantage point. This restricted the number of patients being observed, although at times it was possible to observe in adjacent rooms. Many nurse-patient encounters were relatively public affairs and could be heard from my vantage point. When a bed was curtained it was sometimes necessary to move closer in order to hear and, on those few occasions when it was impossible to hear, the nurse was asked to report what had taken place.

To attempt to obtain data about encounters engaged in between patients and all categories of staff meant sometimes wishing to be in different places with different patients at the same time. This happened for instance when one patient attended a weekly review clinic while another went for X-ray. It was then a case of working out priorities in terms of the data likely to be yielded and asking those patients not directly observed to render an account of what had transpired in my absence. Patients began to volunteer their own information to me and acted then as informants. This kind of observation took place in the months August to October 1972 and is more fully discussed in Chapters 6 and 7.

The succeeding six months were spent in both wards collecting data in specific situations; at review clinics, ward rounds, nurses' report sessions, when consultants discussed patients with ward staff and at informal staff and patient gatherings. Leads obtained in these situations were followed up at successive meetings and through informal interviewing with both patients and staff.

While it was relatively easy to tag on to ward rounds or be present at review clinics, observing patient groups presented some problems. Obviously I was not one of them and no member of staff spent time in this way. Initially patients were puzzled by my presence and focussed their attention on me. Gradually however, by confining observations to a limited number of rooms, thus gaining a degree of familiarity with a smaller number of patients and justifying my presence by saying there was 'nothing much happening elsewhere' patients began to accept my presence.* They came to discuss their illness freely in my presence, something they would not do with nursing staff. Gradually I became more active in my search for particular situations. Initially many details were recorded but later observation became selective in accordance with particular emerging hypotheses.

It was evident that I still had insufficient direct observations of nurse-patient interactions and accounts from nurses of what they hoped to achieve in encounters with particular patients. Comments had been passed by a minority of nurses that they found direct observation created unease and they felt inhibited in what they discussed with patients. Thus Fox's⁽¹¹⁾ comment that situations will revert to normal once observation is established, was not appropriate.

One way of removing my presence from interaction was to observe from a distance and then ask nurses what had taken place. I would be less directly involved and at the same time gain the nurses' interpretation of events. By recording all of the reported events I would also reduce bias of selecting 'good' or 'bad' nursing examples.

*While more female patients were observed than males, qualitatively there was no difference in the way illness was discussed.

It was agreed after a discussion with senior nursing staff and a further discussion with staff on Ward 1 that this kind of data collection would proceed so long as a trial of one week indicated that demands on nurses time would not be excessive. Accordingly four 4-bed rooms in Ward 1 were observed during January and February 1974. At the request of a senior nurse this type of observation was confined to Ward 1 where staff relationships were considered more equable.

Observation data were therefore acquired using different techniques. These data, together with ⁱⁿformal interviews, facilitated the construction of patient careers and assessment of how they conceptualised their illness and were responding to it. Explanations of staff and patient behaviour were also developed.

Recording Observations

I was aware of anxieties generated in staff by notetaking at the scene of action while I was also aware that memory lapses would occur if some kind of immediate recording was not engaged in. A number of different techniques were employed in different situations.

While I was observing for several hours each day in a four-bed room I wrote detailed notes of what happened. At that time I was timing interactions and also recording which nurses interacted with which patients. For this purpose I had a clip board with a time sheet and a watch attached to it. On the reverse side of the board was another sheet on which I jotted down the interaction number and a description of the activity engaged in and conversation. These notes were then expanded during the long gaps between activities while the interactions were still relatively recent. This activity helped counteract the boredom of maintaining an observer role when

there was no action to observe. When patients went from this room and I accompanied them I was able to record in a small note-book a brief memo of what happened to expand later.

Noting events on a ward round of over fifty patients proved to be less difficult than one would imagine. The nurse accompanying the house officer took the ward kardex and occasionally wrote instructions. This break in the continuity provided sufficient time to note anything considered important. Sometimes this amounted to no more than a patient's name and a key word or phrase to jog my memory after the round when as full a transcript as possible was made in a small room allocated to me. Sometimes it was not even necessary to write down during the round, such was the brevity and repetitive nature of much of what took place. Events significant to the particular focus of interest were easy to abstract from all that went on and over time different information was sought to expand categories.

Opportunities were similarly available for note taking at review clinics when the doctors recorded notes after successive patients. At nurses ward report sessions some nurses themselves engaged in note taking and so my writing activity was not out of place.

Nurses' reports of their interactions with patients were recorded verbatim on sheets specially prepared for the purpose to include also details of which nurses and patients interacted, duration of interaction, initiator and activity engaged in (see Appendix I).

The brief memos and notes made in pocket note books or on the clip board were expanded and subsequently filed chronologically in loose leaf folders. These notes consisted of all types of observation, informal interviews, and transcriptions of ward reports.

Field notes also contained introspective comments on what I was observing and on how I perceived others as reacting to my presence.

Interviews and Questionnaires

Formal interviews were held with two groups of respondents, nurses and relatives of patients.

A total of twenty-eight interviews were conducted with all grades of nurse up to ward sister as well as nursing auxiliaries. After the study had been underway for three months, interviews began with student nurses allocated to the unit. These were conducted just prior to the students' being transferred elsewhere. Formal interviews with permanent staff were held in Ward 1 at the end of 1972 and during the following spring in Ward 2. By that time it was possible to formulate questions specific to observation data as well as ask nurses for explanations of their behaviour, their education, experiences of communication with patients, as well as their beliefs about communicating information to patients with cancer, and their families. All such interviews were conducted in private. They were focussed on specific topics about which I knew I wanted information but opportunity was also provided for nurses to elaborate on experiences with patients and their reactions to them. The interviews were structured only to the extent that key questions were included at some point. Nurses were informed that I wished to interview all nurses working in the ward and that the information given in interviews would be confidential and used in such a way that no-one would be identifiable. Two trained nurses were omitted after several unsuccessful attempts had been made to arrange an interview. During the pilot exercise student nurses had been interviewed with and without tape recorder to assess the quality of

data yielded. Whyte⁽¹²⁾ points to the problems of changes in focus due to note taking during relatively unstructured interviews and in the present study it was considered essential that some ongoing record of the interview be maintained. The tape recorder had not been upsetting to nurses during the pilot exercise. However, in the main study a staff nurse and a student nurse said they would prefer not to be recorded on tape and in another two interviews while agreeing to the recording it was obviously so distressing that the machine was switched off. In the remaining interviews the tape recorder was switched off toward the end of the interview and the nurse encouraged to continue her account. Some elaboration was generally engaged in at this point but no significant new data emerged.

The interviews with nurses provided the opportunity to acquire data, not available through observation, related to their assumptions regarding patients with cancer and the effects of information, how they conceived their own role and its relation to medical staff and what they considered as problems specific to their Department. Interview data also provided checks on the internal validity of observation. Both methods of data collection when used alone are regularly open to criticism. By using both techniques it was possible to compare what nurses said they did or would do in a specific situation with what was observed to happen. The data elicited by interview in no way contradicted what had been observed in practice.

The second category of respondent to be interviewed were the spouses of patients. This was the primary source of data about relatives since they were observed only rarely in conversation with patients, nurses or the house officer. A sample of thirty-four spouses of patients having radical radiotherapy were interviewed to ascertain their conceptualisation of the illness, the nature and

sources of information they had received, how it had been imparted and its effects.

Interviews with relatives were focussed and structured to the same degree as with nurses. These were conducted in private in a small room on the ward or in the relatives' own home if they chose this location. The same unobtrusive cassette tape recorder was used as with the nurses but, by comparison, no spouse objected when permission was sought to use it and none showed any anxiety that it was there. The average length of these interviews was forty-five minutes with a range of thirty to ninety-five minutes.

Self completion questionnaire data were also collected from a sample of 111 relatives. This represented a 77% response rate to the questionnaires distributed. These data were aimed at providing some quantitative assessment of contact between relatives and staff and a superficial overview of the nature of the topics discussed.

In both the interview and questionnaire studies, relatives were approached after the patients' permission had been sought. Patients were informed that I was then engaged in a larger study of patients in hospital and I was at that time interested in learning something of the facilities provided for relatives. I later asked relatives if they would be prepared to complete a questionnaire at the time the patient was ready for discharge and arranged to provide this at their last proposed visit prior to the day of discharge. They were asked to return the questionnaire to the ward on their last visit or to return it by post for which purpose all questionnaires were given with a sealable stamped addressed envelope.

Relatives who were interviewed were informed that as well as being interested in facilities for visitors I was also interested in learning what life was like for those at home while the patient

was in hospital for a month or more. None of the relatives asked to participate declined.

Role of the Observer

Being a participant observer entails engaging in ongoing social processes in the research setting and developing a role which will be acceptable to research subjects, while enabling the collection of data. A reciprocal relationship exists between the role developed and available data.

Olesen and Whittaker⁽¹³⁾ describe the processes of role making and distinct phases of engaging in fieldwork. In the present study a degree of role conflict was anticipated by my now being a researcher in a setting in which I was formerly a nurse. Having to gain acceptance by diverse groups was also expected to be a problem since I wanted to observe in different groups yet to be able to move among them to an extent manifested by no other person in the Department. This entailed developing a marginal position vis-a-vis all of the main social groupings. McIntosh reports similar unpleasant feelings deriving from his perception of playing a marginal role.⁽¹⁴⁾

Difficulty was experienced in portraying a research role which nurses could understand for I was so obviously not doing nursing. Early in the study in a misguided attempt to establish good relationships and prompted by some comments on my apparent inactivity, I engaged in some nursing duties at a time when nurses were working under extreme pressure, only to find that this behaviour was interpreted as meaning that I could be called upon to assist at other times. To have complied with requests to help would have restricted both nurses' activities which I wished to observe and my own activities, placing me further in the nurses role than was desirable. Accordingly

I had to disengage from this role and reinforce the fact that I was primarily a researcher. I continued to try to be helpful however and engaged in some menial tasks which did not involve patients, like finding people to answer the telephone and passing on messages. Although I attended meals with nurses and joined in some formal and informal meetings, I was also barred from attendance on some occasions and had to learn to live with a degree of isolation.

Some nurses regularly discussed matters of personal importance to them, however, seeking advice about case studies they were preparing or asking what to do in a particular nursing situation. This degree of intimacy meant I was also the recipient of confidences about other members of staff and the various conflicts among nurses and between nurses and doctors. A neutral stance was not easily maintained while trying to encourage intimacy sufficient for nurses to discuss problems associated with communication.

I was isolated to a great extent from medical staff, but this was anticipated since my observations were confined to restricted events and medical staff were observed in both formal and informal settings only when nurses were either present or were customarily present. Some doctors however found my presence disturbing and, because I did not spend a great deal of time with the consultants or registrars, never really came to know them on a personal level. Some did not see the relevance of the study. Its interpretation by at least one consultant was summed up at the time of seeking permission to extend the study to include relatives when he sent me an article⁽¹⁵⁾ on complaints procedure, suggesting I was looking for complaints against the staff.

Exposure to a small number of patients for long periods each day resulted in knowing more about them than did the staff and

predisposed to intimacy. I was anxious that patients would not respond to me as a nurse and seek information or otherwise interfere with their interactions with nurses. In order to disassociate myself from the nurses' role, as well as not wearing a uniform or engaging in nursing duties, I reinforced that I was not a hospital employee but based on the University. I further distinguished myself from nursing staff by engaging in activities which usually included only patients - sitting in a group, waiting with other patients for treatment, drinking tea with patients, sitting in the sun lounge. Although patients regularly asked for information it was not possible to reciprocate. To have been informative about the organisation of the Department or the location of the hospital shop and cafeteria, for instance, could have generalised to requests for other types of information related to treatment or illness. As it happened, this occurred rarely. It was easier to play the role of naive observer with patients than it was with staff. To maintain a relationship which would not entail my divulging information resulted in directing patients to ask others for the information they sought if it related to their stay in hospital. Such an event occurred early in the study. A few days after accompanying a patient for a lymphangiogram, the patient subsequently heard his doctor use the term "lymph nodes" when discussing his treatment with a group of medical students. The patient, on our return from the treatment floor, asked:

Patient: "What are these lymph nodes that Dr. S---- mentioned down there?"

S.B. "What was this?"

Patient: "When he was explaining the treatment to the students, he said something about the lymph nodes and planning treatment up to here" (pointing to his treatment fields).

S.B. "Oh yes. Well you remember when you had the X-ray the doctor explained about the lymphatic system. Well it's part of that, but if you're wondering maybe you should ask one of the staff."

Patient: "You know fine what it's all about only you won't tell me. You won't say things outright. That's a typical nurse!"

S.B. "What makes you say that?"

Patient: "Well you won't bother to explain things. Ask somebody else, always the same. O.K., I appreciate you're not really a nurse here but you're bound to know about things like that, but forget it. I'll be seeing Dr. S---- end of the week. I can ask then."

This patient never did ask a member of staff but no sustained ill feeling was perceived after refusing him this information.

As with staff, patients at times made available only partial information because of my marginal position. One patient reported to me that the husband of another had seen the consultant and had learned of a very grave prognosis for his young wife. This proved to be correct, but the patient was not prepared to divulge how she came to have this knowledge. The danger of becoming too involved was always present and this was apparent when one patient remarked:

"At the beginning you were very reserved, now that we are friends I like you much better",

while with another I allowed myself to be cast more in a nursing role than was appropriate and she asked that I bathe her one day.

Striving to maintain a role such that I did not over identify with either nurses or patients proved stressful. In striving to maintain an uncomfortable marginal position, I portrayed an aloofness to some nurses which was unintended. Relationships with nurses were also interfered with through being cast in the role of critic. This was exacerbated by the contents of a confidential document related to communications in the Department, which was asked for by the senior doctor, being passed down the nursing hierarchy to ward staff. Some reinterpretation of the document occurred. Subsequently, some effects of nurses communication which were raised as discussion points

at a meeting between myself and the nursing administration were ruled beyond the remit of the study. Later in the study my indirect request to a nurse on behalf of a patient in severe pain was, not unreasonably, interpreted by the nurses as interference. These were serious errors of deportment, partly attributable to an over-identification with patients whom I observed continuously for several hours every day and whose suffering I observed but was powerless to relieve. The setting of limits on active participation and the urge to lapse into a nurse role in this context while being powerless to enact it, created intolerable conflict and engendered the behaviour which was subsequently interpreted by nurses not as being constructive or attempting to assist patients but as condemning and interfering with nursing staff. On occasions, when tempted to interfere, I simply left the scene.

"When Mr. T. asked Nurse F. to get his wife I wanted her to do it. Then when she insisted on sending him for treatment despite his and the porter's protestations, I was so tempted to say 'Can't you see the man's telling you he's dying?' When he died forty minutes later I felt so upset I had to leave. I should be able to observe impartially yet I'm making judgements about this kind of incident and the nurse's behaviour. This is not relevant to the focus of the study yet it interferes."

(Fieldnotes 18th August 1972)

The ward was not visited on the next day.

Yet another role problem encapsulated the study, that of resocialisation into a nurse's role while simultaneously playing a research role. This came about by re-entry into the profession as a nurse in a research post in a University Nursing Department. Former nursing experience, ending some five years before beginning the present study, was that of a conventional training and staff nurse position. The intervening five years, spent as undergraduate and post-graduate student, was experience of a different order. Entry into and contact with colleagues in the Department of Nursing Studies resulted in developing an awareness of nursing as a discipline

very different from my former conceptualisation. Consequently this further personal development and a different professional ideology created tensions which had to be resolved during the time that the study was in progress. Although this role problem is tangential to methodology, such was the magnitude of the personal effects and influence on perspectives of the subject matter of the study that it would be a serious omission not to mention it. Having to come to terms with these sources of role strain and role conflict added to the difficulties encountered in conducting the study and in no small measure contributed to the breaks between spells of data collection and delay in writing about it.

Analysis and Interpretation of Data

As already indicated, data were collected in a number of different situations and by different methods over the period of fieldwork. The data eventually contributing to the final interpretation were:

- recordings of observation and informal interviews
- recordings and tape transcriptions of formal interviews
- recordings of nurse report sessions
- recordings of nurses' accounts of interaction with patients
- questionnaire responses
- documents in the form of patients' notes and nurses' kardex
- introspective comments.

Two principal types of analysis were carried out. A quantitative analysis of interaction data focusing on the frequency, duration, verbal and nursing activity content of nurses' interaction with patients. A quantitative analysis was also performed on questionnaire data related to communication between patients' families and hospital staff. These data were computer analysed, primarily using the

Statistical Package for the Social Sciences.⁽¹⁶⁾ More precise details of the derivation of categories used in this analysis will be presented in conjunction with the data.

The interview data from spouses of patients undergoing radical radiotherapy were also numerically analysed but, because of the small numbers and more complex nature of the data, these were hand analysed.

The second and principal type of analysis, used in conjunction with data collection, was analytic induction. Robinson^(17, p.813) abstractly describes the steps involved in logical induction:

1. A rough definition of the phenomena to be explained is formulated.
2. A hypothetical explanation of these phenomena is formulated.
3. One case is studied in the light of the hypothesis, with the object of determining whether or not the hypothesis fits the facts of the case.
4. If the hypothesis does not fit the facts, either the hypothesis is reformulated or the phenomenon to be explained is redefined so that the case is excluded.
5. Practical certainty may be attained after a small number of cases has been examined, but the discovery of negative cases disproves the explanation and requires a reformulation.
6. The processes of examining cases, redefining the phenomenon, and reformulating the hypothesis is continued until a universal relationship is established, each negative case calling for a redefinition or a reformulation.

Employing analytic induction requires the processes of data collection and data analysis to go hand in hand. Analysis does not occur primarily after the completion of data collection but is an ongoing process which occurs throughout, from the beginnings of abstracting first order categories from the data collected, and continues throughout the synthesis of the analytic framework, using sampling in accord with theoretical propositions (theoretical sampling) and the constant comparative method entailed actively seeking data.

pertinent to developing and verifying hypotheses and actively searching for negative cases which would force a reformulation of the hypothesis.

To take an example, an initial central hypothesis was that patients would seek information about their illness through both the formal and informal social networks if such information was not volunteered in the formal network. While data were collected about information seeking behaviour by patients it became evident that much greater specificity was required regarding the kind of information sought as well as the categorisation of patients according to their state of awareness and desire for particular types of information as this affected information seeking processes. The different functions of information obtained in the formal and informal networks was also elaborated such that, in terms of diagnosis, the patient who wished to know could learn from informal sources and formal information was purely confirmatory.

In this way unsophisticated hypotheses were refined as categories of patients evolved from the data, associated with properties of patient behaviour related to information seeking, interpretation of information and frames of reference. New data were then sought in the light of more refined hypotheses. This included a reanalysis of data recorded extensively earlier in the study, in accord with theoretical sampling, in effect engaging in what Glaser and Strauss call 'collecting data from collected data'.⁽¹⁸⁾

The mechanics of coding data collected through observation consisted of implicit coding of what was observed in accord with the emergent analytic framework. Data were also explicitly coded on 'Cope-Chat' cards in accord with categories initially thought important and more refined categories emerging later. By recording in this way, data could be placed within a number of different categories without having to be repeatedly rewritten and later

hypotheses verified without always having to collect new data as already observed events were slotted into appropriate categories. The chronologically recorded data permitted monitoring of the processes of communication over time.

As Denzin⁽¹⁹⁾ notes, analytic induction is especially useful for the development of processual theories. Communication about a cancer diagnosis and prognosis was conceived not as a static phenomenon but as a social process. Similarly nursing care is considered by the author as processual in nature. So analytic induction is appropriate on both counts in developing theory to interpret social processes and, subsumed within this, to understand nursing processes.

External Validity

One of the most frequent questions raised about participant observation together with intensive investigation of one organisation is that of external validity. To preserve external validity entails demonstration that the case study and theoretical derivations are representative of the larger population to which generalisations are made. Both senior medical and nursing staff in the present study regarded the prevailing policy on disclosure as conservative and attributed it partly to a remaining influence of the long standing former head of Department. They expressed concern that the Department would be revealed as atypical or less 'progressive' than others. The setting was chosen for convenience irrespective of whether it constitutes a good, bad or indifferent sample of the population to which it belongs, with the emphasis on explaining rather than evaluating communication practices. While the passage of information about cancer may vary in different settings or may

change over time altering the total milieu in which patients are treated and hence their desire for information and consequent behaviour, this would not invalidate the present study on the grounds that resulting theory could be reformulated to handle different contingencies.

Correspondingly, should the characteristics of the staff sample change, say to doctors who were more willing to disclose or to nurses who held a different professional ideology, then resulting theory would have to be reformulated to handle this heterogeneity.

Retrospective comparisons made with other settings and from discussion with many professionals, together with the very similar findings of McIntosh⁽²⁰⁾ suggest that the study has a high degree of external validity. Whether this is the case can only be gauged by reading the report.

Internal Validity - observer effects and bias

"The creation of the role of participant observer inevitably introduces some degree of reactivity into the field setting." (21, p.204)

Initial reactions to an observer were anticipated but, because fieldwork was to be conducted over a long period, it was expected that subjects' behaviour would stabilise. However, some residual effects were bound to exist. This raises the question of the extent to which residual observer effects influence the internal validity of the study.

Comments from doctors and nurses about feeling awkward while being observed or making jokes about recording diminished over time. However radiographers commented that accompanying patients into the machine rooms created an unnatural situation. Some nurses were observed reluctantly. One trained nurse felt uncomfortable reporting

her conversations with patients. All of the accounts rendered by this nurse were so brief that they could not have been faithful representations. Another reported being uncomfortable and sometimes not discussing things with patients she might otherwise have done had she not been observed. On asking if the patients suffered on account of this she replied "No, not at all. I waited until you were away and then I would pop in to see them".

A point was made of asking nurses whether my presence was disturbing. Typical reports indicated effects unlikely to invalidate the data.

Staff Nurse: "We're so busy here I don't think about it anymore. I just get on with what I have to do and hope I'm doing it well enough."

Staff Nurse: "It was a bit embarrassing at first. I mean when you know everything you say is being listened to and may be written about. Not now, I'm used to it and I forget half the time you're even around. No, on the whole I'd say it's all right now."

Student Nurse: "When you know you're being watched you just try to do the best you can. Well at least I try my best, maybe a bit harder than if you're just plodding on."

When ward sisters were asked whether adverse effects were present, they reported that students did not mind being observed, they were used to it in their day to day work; some of the nursing auxiliaries were a little embarrassed, and trained staff felt inhibited. Altschul argues that one would expect changes in nurses' behaviour due to being observed:

"to have occurred in the direction in which nurses themselves thought their behaviour desirable..... their own bias would be increased and therefore observer effect could not invalidate the investigation." (22, p.52-53)

The same may apply in the present study.

Given the congruence between data collected in different observation situations over a prolonged period of time, as well as

through interviews, there is no reason to suggest that normality was so disturbed as to invalidate the study. Nurses who served as informants did not vary in their willingness to report incidents which had occurred in my absence or discuss issues which arose.

Patients, like nurses, were asked if my presence was disturbing and each was asked to inform me if at any time my presence was not desirable. No direct comments of this kind were received and many patients said they welcomed some extra company while waiting for a test, treatment or to see their consultant. One indirect comment received through the Hospital Chaplain was that a patient had reported he was never able to see his doctor alone, there was always another doctor or a nurse or myself present and this deterred him from discussing his illness. I avoided attending the next and final review sessions with this patient and, although he was alone with his consultant, it was reported that the patient sought no diagnostic information. He strongly suspected malignancy but preferred the uncertainty of not being really sure to having his worst suspicions confirmed. My presence or that of others served as a convenient reason for avoiding discussing his illness.

Being an observer can produce both inhibiting and catalytic effects. I was concerned that this might be so, especially among patients with respect to how they discussed their illness among themselves. I was aware that I could be construed as part of the informal information network and hence fair game for information. In fact I was rarely asked for information. There was nothing to suggest that patients discussed their illness any differently because I was present. There were no observed differences in content whether I was directly involved in the conversation or simply listening.

Later analysis will demonstrate that the patient's state of mind regarding his illness would influence his information seeking behaviour and my presence would be unlikely to alter this. Some patients spoke of their feelings regarding their illness with me but whether this would alter the nature of their expression to others, had they not spoken with me, is again dubious given the consistency of patient adaptation patterns.

Information was not passed on to staff or patients when it was related to the focus of the study. Rarely, on other occasions I did act as messenger. For example, while interviewing the common law wife of a patient it was evident she had arranged to tell me about her financial and legal problems and had ready some accounts to show me. In no small measure her problems were due to the erratic behaviour of her husband caused by his brain tumour. The wife was near to exhaustion. Since I would involve neither the woman nor her husband again in the study, with her consent and knowing that the patient was soon to be discharged, I informed the ward sister of her problems.

Engaging in this type of activity did not produce obvious effects on data or on relationships between myself and research subjects.

Several potential sources of observer bias are immediately evident in a study of this nature and subject matter. It is well nigh impossible not to hold a strong value position regarding the patients' right to information and the nurses' role in this process.

At the outset of the study I firmly believed, and this was reinforced in much of the literature, that most patients would prefer, and had a right, to know the details of their diagnosis, and that to know would be of benefit to both the patient and his family. This view is enmeshed in a cluster of other beliefs - informed consent,

the need to have information about the condition in order to be able to adjust to it, the patient and his family being treated as a unit, the contract being first with the patient and so on.

Very quickly it became apparent that formal telling was far less important to patients' awareness than other information sources. Besides many patients did not want to know the full details of their condition. The data forced a reconstruction of previously held beliefs, suggesting that the data were more robust than my belief system.

A second potential source of bias lies in the nursing ideology of the author and values related to nurses' professional autonomy. This was compounded by former experience of working in the Department in which the study took place and observing, from a different perspective, activities in which I had once taken part and which now appeared at variance with personal professional values and beliefs. It had to be constantly borne in mind that the purpose of the study was to describe and explain events, not pass judgement. Whether the intrusion of values created invalidity can be judged only by reading the study and interpreting the findings. Awareness of potential bias is a powerful antidote.

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CHAPTER 4

DOCTORS' IDEOLOGY AND THE MANAGEMENT OF UNCERTAINTY

This chapter deals with the ideology giving rise to doctors' communication practices, describes how communication was managed and explains this in terms of the management of uncertainty.

Doctors' Ideology

All of the doctors believed that not all patients could be told their diagnosis, and the majority subscribed to the view that most should not be told. There was also a shared belief that, excepting where prognosis was excellent, prognostic information should not be imparted. Patients should only be given information about their condition which would cause them no distress while encouraging them to participate in treatment.

This meant that patients should not be told that they had cancer or given an unfavourable prognosis unless circumstances were such that this was judged unavoidable. Information given about the illness and its treatment should avoid reference to cancer and be couched in optimistic terms.

Dr. P. "I rarely tell patients the truth about their case. I try to avoid letting the diagnosis become established and I always give a much better prognosis than is really the case."

S.B. "Why do you do this?"

Dr. P. "Well it's better to paint a bright picture. After all, what's the point in destroying hope?"

This ideology was grounded in a belief that knowledge of the real state of affairs would be detrimental to the patient. It was likely to give rise to a number of immediate and longer term undesirable reactions. These anticipated reactions would be more harmful than any effects of not knowing the real diagnosis or

prognosis. References to cancer or malignancy were avoided when the illness, diagnostic tests or treatment were discussed and communications were tinged with optimism about the outcome of the illness and the future.

To have told would have allowed patients to bring into play their own conceptions of cancer. It was assumed that these beliefs associated cancer with unpleasantness and death. This would have precluded hope and, as well as being harmful to patients, would have created management problems for doctors.

Dr. H. "There is no point in telling patients they have cancer when they just give up the ghost. On the contrary patients can live out their lives happily not knowing. I've seen it happen. A patient gets to know he has cancer. He just gives up and turns his face to the wall. He's dead within a matter of weeks."

Dr. T. "Once a patient learns the truth then they never have a minute's peace. Every twinge, every minor upset, they are wondering if it has spread, what's the cause of it. Then they badger everyone with questions and want to be reassured the whole time. It's just not worth it from anyone's point of view."

Communications were concerned with preventing patients realising that they had cancer or an unfavourable prognosis. An assumption prevailed that most patients had no desire to know, and was reinforced by few patients asking in a direct manner. However, also acknowledged was that being treated in a department of radiotherapy, whether or not preceded by primary surgical treatment, provided a very strong clue to the nature of the illness. That patients could experience this treatment and be in this Department yet still not ask for details of their diagnosis further added to the belief that most patients had no wish to have cancer confirmed. Thus although patients suspected, sometimes very strongly suspected, that they had cancer, not seeking absolute confirmation allowed the possibility to remain that the illness was not cancer. Doctors sought to avoid jeopardising

this possibility and with it the hope that the illness was something else and that the future was hopeful. To have destroyed this hope would have been brutal insensitivity; communications were intended to sustain hope. Consistent with this reasoning was the belief that, although some patients were known to have learned their diagnosis elsewhere or earlier in the course of their illness, there was no point in resurrecting discussion of diagnosis with amplification of details of the illness. Of course it was difficult for doctors to be sure of the prognosis while there was no doubt that patients had cancer, there were difficulties in establishing prognoses with real certainty. Doctors were able to recount experiences of patients whose life span was widely at variance with their assessment. Doctors believed that patients did not want their prognosis, and certainly did not wish to be given any time scale.

This does not mean that all patients were considered not wanting to know or likely to react badly to being told. It was acknowledged that some patients did want to know and would benefit from this knowledge.

Dr. W. "I believe now that more patients can be told their diagnosis than I once did, and I more often tell my patients now."

Only part of the patient career was being investigated. Patients were usually first assessed by Consultants at the place of diagnosis or at an out-patient clinic, and it was there, at their first meeting prior to admission, that doctors said they were likely to impart a diagnosis of cancer. This study was confined to the time after patients had been admitted.

The individual characteristics of patients were asserted as determining who should be told. Avoiding disclosure was not absolute. When it was considered that patients would benefit from such

information and would not react adversely to it, then it was asserted that they should be told.

Dr. B. "So long as there is no reason for the patient not to know, like a psychiatric condition, or a low I.Q. then they can be given a pretty good idea. Some people have business affairs to see to or other arrangements to make, so it's far kinder to be honest."

However how patients would respond to such information and which patients would react in a desirable way was unpredictable. The prevalent assumption was that patients would not react well to knowledge of their diagnosis or prognosis.

Dr. K. "In my experience, if you tell patients they've got cancer, they can never get away from it. There's no point in making life miserable. Take Miss A. She's weepy and keeps on asking what's at the root of her trouble but I won't tell her. She would just crawl into bed and give up. There's no point in making what life she's got miserable by telling her it has spread."

This assumption was reinforced by dramatic accounts of patients who had given up all hope and waited for death, who had become very depressed and suicidal or who had exhibited strong emotional reactions at the time of being told, when the doctor had assessed a favourable response. Further problems were anticipated in managing patients who knew their diagnosis when they sought further information about new symptoms, why other tests were being performed, additional treatments and other indications of a worsening prognosis. Disclosing an accurate diagnosis would leave the doctor prey to difficulties in managing other information with the possibility of the patient becoming dependent, emotionally, upon him. Difficulties would also be increased when patients who had been told their diagnosis apparently upset other patients by their emotional outbursts. In the absence of valid ways of assessing in advance how patients would react to disclosure it was considered more humane and in the best interests of patients to avoid disclosing the real state of affairs.

One consultant told students at a lecture that:

Dr. S. "The general policy here is not to be too open. We tend to fob them off a bit with wee stories. Now, the problem is that patients could take a different meaning out of what you say. If I told Mr. T. he had lymphosarcoma he would take the worst possible meaning out of it. Whereas we have another patient being re-treated after nine years. Therefore it's wrong to rush in and tell. It's best just to give some idea of what we are going to do treatmentwise, and rather tell the relatives and give them a more complete story."

Dr. T. "Not telling patients may create some problems but to tell them would create a far greater set of problems for everybody concerned. And this is not only the patient but for the family and those who have to look after him."

Included among the latter was the doctor who actually had the task of telling. As one house officer said,

Dr. H. "Let's face it, it's not something that anyone of us enjoys doing. I would do almost anything before I'd tell somebody that they've got cancer and they are going to die. It's usually better for everyone concerned not to bring it out into the open."

Practices of information management associated with ideology therefore serve more than one function. While aimed at avoiding harming the patient while engendering hope, they also relieve the doctor of the unpleasant task of breaking bad news. This raises the question of the derivation of behaviour. As indicated the doctors held a number of assumptions about information and patients, assumptions incorporated into ideology, and which explain practices. Equally however such assumptions may constitute an affirmation for a policy which is adhered to for other reasons, including avoiding unpleasant disclosures. The origin of practices therefore is open to question while the practices themselves, avoidance of words like cancer and malignancy and indications of a poor prognosis, while conveying optimism, are entirely consistent with and empirically validate the ideological position indicated by the doctors.

Operationalising this ideology presented problems because there was no absolute taboo on disclosure. Some patients, those for whom telling was regarded as more beneficial than harmful, could be told. In the main, however, it was deemed preferable for patients who wanted to know to remain uninformed rather than risk destroying hope by telling. Which patients therefore should be told?

Communication problems stemmed from the dilemmas of carrying out such a policy.

Ideology and Uncertainty

Davis^(1,2) had made explicit the ways in which uncertainty influenced communication about illness. While cancer may pose clinical uncertainties over diagnosis, in the present study this was a minor issue. All of the patients had already been diagnosed elsewhere. In only one observed instance was there any clinical uncertainty over diagnosis. This was in a patient with an abnormal lesion seen on his chest X-ray and which was not amenable to exploration by any of the usual diagnostic measures. Because the patient had had a previous carcinoma of prostate gland the lesion was assumed to be malignant and treated accordingly. Occasionally clinical uncertainties arose in relation to classifying a tumour or locating the primary site, but there were no difficulties in deciding that the patient had a malignant disease.

By comparison a great deal of uncertainty attended clinical aspects of the illness associated with prognosis. These included the extent of the illness, whether it had spread, the underlying cause of symptoms, likely response to treatment and expected life span. Even when some aspects of uncertainty were established, like confirming that the illness had metastasised or how a tumour had

responded to treatment, this was not conveyed to patients. Occasionally some favourable news, like a clear X-ray would be divulged, but the patient was unlikely to have been told what was being sought in the first place. Certainty did not prompt disclosure and clinical uncertainty, while a factor in prognosis, cannot account for withholding diagnosis or ascertained facts associated with prognosis. Other sources of explanation must be sought to account for communication practices.

These lie in the difficulties of assessing patients' likely response to information about diagnosis or prognosis. There were no accurate ways of screening patients as a basis for action regarding telling. Doctors had to function on the basis of their own limited experience,* and assumptions about patients, which left them with uncertainties about the likely reactions of individuals. While some doctors theorised that it was possible to tell particular groups of patients - the professional classes or highly intelligent - there were always the occasional exceptions to the rule, which precluded using any single criterion as a basis for decision making. There were no other reliable methods available to assess patients, only assumptions about likely response which constituted shaky grounds for action. Since patients could not be assessed individually, attendant uncertainties had to be contained and managed while communication proceeded. There were different ways of doing this.

Doctors avoided relating communication to individual patient characteristics. Rather, they adopted a generalised practice of avoiding using the words cancer or malignancy. Patients were not

*Limited in this sense applies to different ways of managing information to patients and following through patient reactions.

told their diagnosis unless it was absolutely necessary to do so. It was never volunteered. Measures used to avoid disclosure ranged from employing euphemisms to down right denial that the illness was cancer.

McIntosh⁽³⁾ found that doctors relied upon half truths rather than down right lying. In the present study however cancer was at times absolutely denied and alternative diagnoses and explanations extended beyond euphemisms which, by their nature, must embody some of the truth.

"No, it is not cancer. It is only an infection."

"It will be due to the blood transfusion causing a swelling."

"The pain is due to rheumatism. There may be a touch of sciatica making it worse."

Such outright disavowals of cancer were never used by consultants, only by registrars and house officers who were less aware of the practices utilised by consultants to avoid disclosure. The latter had developed an array of euphemistic and ambiguous expressions which, while not denying cancer, did not impart the whole truth. Thus cancer was referred to as 'suspicious cells', 'it looked nasty so better to be treated', 'it's the type of thing better attended to early on', 'it's nothing we can't do something for'.

Labels which were open to more favourable interpretation than cancer included 'blockage in the bowel', 'a wart in the bladder', 'an ulcer at the neck of the womb'.

Of course it was possible to avoid telling by simply withholding much of the information about the patient's illness. It was germane that communications sustain the patients' hope. This would be threatened and suspicions raised should contradictory information be given. Different doctors involved in the care of the patient and

the same doctor over time had to take the same line. At any one time doctors were responsible for many patients. Practices of information giving had to be generaliseable between patients, between doctors and for the same patient over time.

In order to fulfil these conditions a number of routines had evolved for communication with patients. These were shared by consultant staff and senior registrars but had to be transmitted to new registrars and house officers who stayed in the Department for only six months.

Routines for face to face conversation with patients were associated with different types of disease at different stages, and having different kinds of treatment. These details of the patient's illness and treatment determined what he would be told rather than his social or personal qualities. It was possible to anticipate the substance of what a patient would be told at a particular meeting with a doctor purely from the illness and treatment categories into which he fell. So long as appropriate routines were employed, consistency was maintained between doctors who were treating a patient, and for a patient over time. It was not the actual words uttered which required consistency but the meaning of what was conveyed. The language used varied between patients in accord with perceived personal and social characteristics - the message intended was less likely to vary within the various patient categories. This applied whether information was volunteered to patients or given in response to the patient's questions. There were routines for volunteering information to particular patient categories and routines for use in response to particular patient questions.

A consideration of individual patient characteristics was espoused as a basis for decisions regarding telling:

Dr. B. "It really depends on the individual patient. I mean there are no hard and fast rules about what you actually say. It all depends on what a patient wants to know and how he will react to it. Some do ask, not many. Even then you can never really be sure yet you've got to make a decision."

In reality, what was said to patients was largely independent of such factors and based on characteristics associated with the illness and its treatment. This is not the same as saying doctors did not attend to how patients were reacting to their illness, whether they were displaying anxiety or their likely response to particular information. They did consider these matters but they were not central to what a patient would be told. Rather, what was told to patients depended on the category into which they were placed and the subsequent implementation of appropriate routines.

Implications of the Routinisation of Communication

McIntosh⁽⁴⁾ outlines three main contributions of the routinisation of communication. First, the assurance of consistency in the sort of information given by staff to patients with similar conditions. This holds only so long as all of the staff are aware of and consistently apply routines. I found that senior medical staff were consistent but new house officers, who had not been able to observe the routines, were unable to use them. This was relevant especially when patients asked questions. House officers were unlikely to volunteer much but were regularly exposed to questions on the daily ward rounds which they conducted with a nurse. Senior medical staff were never present and house officers had limited opportunities to observe their interactions with patients. Sometimes the nurse could take over when questions arose but questions were generally directed to the doctor and traditional role distinctions demanded

that he answer. Under such circumstances contradictions occasionally arose and patients were able to acquire information by comparing responses of different staff members.

Second, routines absolve doctors from having to take decisions about individual cases. At the sessions when consultants reported back to the ward after a review clinic or ward round of selected patients, what to tell the patients, which patients to tell and what patients had been told did not feature in their discussions. Such ward meetings were concerned with treatment, tests, discharge arrangements and the day to day management of troublesome symptoms. Senior medical staff reported decisions made elsewhere regarding investigations and treatment and reported results of tests while house officers and nurses contributed information related to symptoms and their management and factors relevant to decisions regarding discharge or transfer. Although at times reference was made to patients' mental state, particularly if they had created a disturbance in the ward, and rarely, whether patients knew the details of their illness, such factors were not related to decision making regarding the management of information by the various categories of staff.

Decision making about which patients to tell and what to say was unnecessary. Ideally, so long as everyone knew the patient's diagnosis, and this was conveyed to ward staff prior to the patient's admission in a brief synopsis of the case notes, and the treatment, similarly conveyed or reported by the consultant on the completion of tests, then the appropriate routine was available. In any case, by asserting sole responsibility for disclosure, consultants did not need to involve other staff in decision making or reporting his actions with patients.

Routinisation however meant that decision making even for consultants was avoidable. All they had to do was employ the appropriate routine. As McIntosh noted, what to tell is linked to treatment decisions. This was most obvious in the present study when disease was spreading and decisions had to be made about whether and how to treat. What was told patients was linked to such decisions. For the majority of patients treatment decisions were made prior to admission and for standard treatments routine communication could be implemented at once. It was only when there was clinical uncertainty that decisions about what to say had to await decisions regarding treatment. Once the appropriate treatment decision had been made by the consultant, this could be communicated to the ward staff and routine communication with patients followed. The less experienced doctors, those not involved in treatment decisions, were at times left wondering what to say to patients because they lacked knowledge of appropriate routine responses. One of the first things a new house officer had to ask nurses was what kind of diagnosis to write on the discharge letters given to patients to take to their General Practitioners. It was less easy for nurses to acquaint them with routines to meet other contingencies and so, as we shall see, house officers became involved in decision making regarding communication with individual patients, either alone or with nurses.

The third consequence of routinisation identified by McIntosh was avoidance of interpersonal conflict. In his study the consultants maintained supreme jurisdiction over telling and this was acceded by junior medical staff. Not so in the present study. The consultants claimed sole responsibility for telling but this was not absolutely conceded by junior doctors or nurses. Thus junior doctors were

observed to tell patients, albeit under pressure, that they had cancer. Conflict arose only when the house officer disclosed contrary to the consultant's wishes, told the consultant and the latter had to reassert his supremacy in such matters.

Dr. K. "Mr. J. asked me if it was cancer. I told him it was, as you heard, but now what am I supposed to do? If I tell Dr. P. I'll get it in the neck. He thinks this is his pigeon. But when a man like that wants to know he has a right to a straight answer. I've had a couple of bust ups already but you can't just shrug some of them off."

When a consultant's displeasure was suspected for disclosing, house officers were less likely to report their actions than when the consultant was regarded as permitting such discretion, in accord with a more flexible policy regarding telling.

Dr. K. "I'll have to have a word with W. about Mr. H. He's asking questions and I'm stalling. W. isn't as bad as some of them when it comes to telling but it's his patient so it's up to him. I don't see any reason for not being frank, it's not a bad tumour. But I had better not barge in again."

The prevailing policy, together with most consultants' desire to maintain sole responsibility regarding telling, resulted in some house officers denying patients information which they felt could usefully have been passed on.

When house officers frankly disclosed this was not something worked out in advance with other staff. Because consultants maintained sole authority and because there was no assessment made for individual patients, there was nothing to discuss. Telling was precipitated by patients introducing the question of whether they had cancer, sometimes in an admission interview, and the house doctor agreeing that it was. He did not know what the patient had been told elsewhere and the patient could have been testing him out. Therefore if patients asked in this context they may be told. When

a house officer and nurse were telling a patient she was going to a nursing home which the patient recognised as a Marie Curie establishment, she said:

"That must mean it's cancer then."

Dr. J. "Yes it is, but you've had it for ten years and look how well you have been. This is only a temporary set back."

Senior nurses also reported conflicts with consultants because, on occasion, they had been placed in a position where they felt they could not deny a patient's request for their diagnosis. Such incidents were not observed to occur during the study, however, nurses preferring to avoid clashes.

Thus conflicts did occur. More often however because there was no discussion of who or what had been told, differences were not aired and so conflict was avoided. So long as the consultants' authority was seen as absolute, there was no need for negotiations regarding who should be told or what they should be told,* and there was no airing of opinion regarding telling.

The other type of conflict which could be avoided by routinising communication was the giving of conflicting information to patients. The use of similar routines by all grades of staff maximised ambiguity and manoeuvrability, permitting the same substance to be conveyed to patients by different personnel while allowing for changes to be made as circumstances warranted. Avoiding giving conflicting information to patients minimised conflict between staff because different information had been passed on. It was when routines were not adhered to that conflicting information was given. Often however staff did not realise they had done this because they did not report

*The negotiation engaged in over informal hospital rules, as observed by Strauss et al. (5) does not apply in this case.

what they had told patients, each assuming that they were taking the same line. Thus one patient was told she would only have five treatments because a) that was all her condition required, b) she would go home and come back again when she was stronger, and c) everything had been packed into five treatments.

The information given patients could also have been at variance with that given either in the diagnostic setting or by General Practitioners. It was only on rare occasions that any information was included in patients case notes regarding what had been told them elsewhere. Consultants presumed that how they managed patients was not markedly at variance with other doctors and that few patients would have been informed prior to admission. Accordingly, they did not ascertain from patients what they had been told nor did they convey to other consultants or General Practitioners the information given to patients. However, since few patients were told they had cancer while they were in the Department and cancer was not usually categorically denied, clashes of information were infrequent. If the General Practitioner or surgeon chose to be more specific once the patient was discharged, then that was outwith the control of the consultants. They told patients only when they were forced to do so.

Clearly from the arguments presented above, uncertainty was a major factor in determining the content and structure of communication. In the absence of ways of ascertaining which patients wanted to know the details of their illness or how they would react if they were told, doctors played safe and attempted to avoid disclosure as far as possible. The ways in which they managed communication are described in the following chapter.

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CHAPTER 5

DOCTORS' MANAGEMENT OF COMMUNICATION

While uncertainty about patients' desires for and potential response to information underlies doctors' communication, doctors were able to use uncertainty to advantage in structuring the content of their communication. In the routines adopted to limit disclosure to patients doctors relied heavily upon what Davis⁽¹⁾ entitled functional uncertainty, a concept extended by McIntosh⁽²⁾ to encompass functional certainty. The concept of functional uncertainty accounts for the projection of uncertainty into a situation in which clinical uncertainty has been established in order to manage interaction with patients. Functional certainty on the other hand denotes the practice of imputing certainty when, in fact, uncertainties exist. This chapter examines how functional uncertainty was used to manage diagnostic information with functional certainty in the case of prognostic information.

Although there was no doubt about the diagnosis, doctors did not use the words cancer or malignancy. Rather, they referred to the diagnosis in terms like 'it looked nasty', 'it's glands' or as 'a wart in the bladder', 'an ulcer in the throat', 'a shadow on the lung'. In themselves, these do not imply uncertainty. However, in the context of cancer as the diagnosis, they suggest that a more specific diagnosis cannot be given. Thus the area affected is denoted - 'an ulcer in the neck of the womb' but no indication is given of the type of ulcer, or wart, or the reason giving rise to the shadow. Similarly, terms like 'nasty patch' indicated something was amiss, but not the exact nature of the trouble.

Symptoms due to spread were similarly referred to in terms implying uncertainty - 'it could be a haematoma after the transfusion', 'these pains are rather like rheumatics', 'it's likely due to a crumbling of the bone'. By implying uncertainty about diagnosis this gave some meaning to the illness while at the same time avoided saying that the illness was not cancer or had not spread which would have been a lie; or telling the truth, which may have distressed the patient.

Doctors in the main did not openly tell patients that they were uncertain, the terminology used was subtle enough to imply it. Among less experienced doctors however, uncertainty was sometimes more clearly admitted to.

Patient: "I wish they knew what it was. I get worried not knowing."

Dr. F.: "Nowadays there's a lot of things we don't know about."

Dr. J.: "We know it's due to pressure but we're not sure exactly what's behind it."

Usually though, doctors were not explicit in saying that they did not know the diagnosis, it was implied in the terminology used. It was only when patients questioned such labels that greater certainty would be invoked that the illness was not cancer.

"No, cancer isn't a word we use because it covers so many different things."

"It's not cancer. It's a softening of the bone."

"It could develop into cancer if it wasn't treated now."

But how could doctors treat something about which they were uncertain? They had to convey to patients that they were giving the appropriate treatment while not disclosing a precise diagnosis. What was communicated had to be balanced between implying uncertainty over the final diagnosis while conveying confidence in treatment. Thus phrases emerged like 'it's the type of thing better attended to

early on'. To call the lesion a wart or ulcer, a blockage in the bowel, indicated that the doctor was sufficiently conversant with the illness to be able to treat it. And to treat it effectively - 'it's nothing that we can't do something for'.

Both the efficacy of treatment and the appropriateness of treatment were stressed, even though the precise nature of the illness being treated was not identified to the patient. Uncertainty about the nature of the illness was sustained along with certainty of the appropriateness of treatment regime and its success.

"We know the pain is coming from the spine but we're not sure exactly what's causing it. Probably something pressing on a nerve. But we'll X-ray you today and then begin treatment right away."

If there was such uncertainty, yet treatment could be instituted, then this conveyed that the illness could not be very serious. A more serious condition, cancer, would have been more clearly identifiable. Thus uncertainty projected about diagnosis had implications for prognosis. If the illness was uncertain, then prognosis may be good. On the other hand, an uncertain prognosis could be unfavourably interpreted. Therefore certainty about prognosis had to be conveyed. Doctors had to give the impression that there was optimistic certainty about the future. How this was done depended on the likely prognosis.

Greater certainty was implied about the outcome of treatment when there were reasonable grounds for cure. This was especially so when patients were treated for rodent ulcer and cure was assured them. With less certain but possibly favourable outcomes, a good prognosis was still conveyed to patients.

"We can almost guarantee you no further trouble."

"After the operation we don't feel justified in withholding further treatment, the results are so good."

"There are few things in life we can guarantee 100 per cent so we can't say this (treatment) will be absolutely certain, but we're pretty sure it will do the trick so we'll start right away."

Even when prognosis was poor, a good outcome was still conveyed to patients, though in slightly different terms:

"Five treatments and it will be better."

"Everything should be all right after the treatment is finished."

"You should expect no further trouble."

"This treatment is the best thing for this trouble. You should feel much better once it is finished."

By implying a relief of symptoms after treatment, prognosis was equated with this resolution of the patient's immediate problem.

Thus uncertainty was imputed into situations of diagnostic certainty while certainty of a good outcome was imputed into situations where no such certainty existed. These measures permitted the doctors maximum manoeuvrability while not disclosing the real state of affairs. By using oblique terminology, only partial information was imparted and this could be manipulated should the patient have made it clear that he wished more definite information. Since there was no way of being sure of the patient's desire for information or reactions to disclosure, the judicious use of uncertainty maintained consistency with ideology, and engendered hope.

Doctors were able to manipulate uncertainty both through what was volunteered to patients by way of explanation of their condition and its treatment and by how they responded to patients' questions. Appropriate routines were available depending on which category patients fitted.

Volunteered Information

Diagnosis

In the department, because doctors did not use the word cancer in conversation with patients, even the most curable forms were not acknowledged to be malignant. Patients being treated for rodent ulcer, a readily curable skin cancer, were not informed of the malignant nature of the condition, but doctors were at pains to stress that it was relatively innocuous.

"This isn't a serious thing you have. It's just a superficial ulcer and after the five treatments it won't be any trouble to you."

"This is nothing to worry about. It's a simple thing and easily cured."

Some of the more serious cancers had special labels applied to them which were shared by different doctors. Bladder cancer for instance was referred to as a 'wart in the bladder'. Cancer of the uterine cervix was called an ulcer, as was throat cancer, while lung cancer was referred to as a shadow on the lung. These conditions were diagnosed elsewhere and the patient could have been given alternative explanations. Patients were not asked routinely what they had been told about their illness by other doctors. However, had patients been informed, applying these labels did not deny that the condition was malignant, and permitted an alternative explanation of the illness. When different labels were applied, these were similar and unspecific enough to be synonymous. Thus when a patient mentioned 'fibroids' in the bladder, the consultant reinterpreted this as a 'growth in the bladder, a kind of wart really'. Another patient was told he had 'some consolidation left after pneumonia' and later, by another doctor, that there was a 'shadow on the lung'. The former could be interpreted as showing on X-ray as the latter, so maintaining consistency of explanation.

At times no such alternative diagnoses were so readily available and so the illness was referred to as 'your condition', 'these nodes', 'this thing', or to the symptoms of the illness, 'this swelling', 'the pressure', 'the inflammation', otherwise to the part of the body being treated 'the treatment will knock out the ovary'. Making such references to the illness neatly avoided having to reveal cancer. Avoiding disclosure was further engendered by explanations of and emphasis on symptoms and treatment.

Symptoms

Not unnaturally patients were concerned about troublesome symptoms and were anxious to have them relieved. Explanation could be focused therefore on the symptoms and not the underlying cause. Since patients were admitted for treatment, and hopefully alleviation of their symptoms, what was said about treatment and symptoms went hand in hand.

"Your breathlessness will improve after you've had the treatment."

"This congestion and feeling of tightness will go away within a few days once we get the treatment going."

Sometimes symptoms experienced by patients were not due to malignancy but to some other, less serious, condition. For instance pain due to haemorrhoids, breathlessness caused by bronchitis, aches due to influenza, and it was possible to dwell on these rather than the illness which had actually brought the patient into hospital.

Another source of discomfort for patients were the side effects of radiotherapy and chemotherapy. At times these were very much more distressing than the illness itself. These symptoms were the primary focus of conversation at weekly review clinics and at daily ward rounds. Although the monitoring and management of such unpleasant consequences of treatment was in itself important, this served the

added function of diverting attention away from the more serious underlying illness. Also the minor troublesome nature of the symptoms was stressed compared with long term benefits.

"You'll be feeling tired for a while after the treatment but in the long term you'll feel right as rain."

One of the more difficult communication problems was associated with symptoms caused by the spread of the illness. This was especially so if the patient knew he had cancer and spread would have revealed a worsening prognosis. These were therefore explained in terms of secondary symptoms without reference to the underlying pathology.

"These pains are due to pressure on the nerve at the spine. After the treatment this should be relieved."

"This breathlessness is caused by fluid collecting in the lung. Once we remove it, your breathing will be much easier."

Treatment and Tests

The majority of patients were in hospital to have radiotherapy and/or chemotherapy. Not surprisingly central to conversation between patients and doctors were the various aspects of treatment - its planning, beginning, duration, onset and the type of side effects to expect, their treatment and special precautions to take. The focus on the various aspects of treatment and the patient's progress through treatment served to detract from the reasons for treatment, why the patient should be having this particular therapy or what it did.

The information given about treatment was routine for specific conditions. Information about the duration of radiotherapy and associated treatments like insertions of radioactive substances, or chemotherapy were routinised. Particular information about the

expected effects was given at particular times during the course of treatment. As well as explanations about treatment being routine, that treatments were routine in their nature was also stressed.

"I believe you've been having some trouble with your back. Well you'll be having five treatments. That is routine for this back condition. Each session will last about five minutes and you'll feel much better at the end of it."

"After surgery it's routine to have radiotherapy. We give twenty treatments, on Monday to Friday each week, and you can go home at weekends."

Coupled with standard information about treatment and directives about side effects, was encouraging information. Patients who attended reviews were regularly told:

"You are responding well to treatment, so we'll carry on."

"You're doing very well and these side effects are just what we would expect."

"The swelling is going down nicely, you'll feel much better soon."

"You are taking the treatment well."

"That looks fine, I'm pleased you're keeping so well."

These comments served the dual purpose of conveying optimistic information to patients not only about their current health but also about their underlying illness. By making such statements this diverted patients from having to ask, perhaps in more specific terms, about the outcome of treatment. If the unpleasant side effects of treatment were becoming severe, it was not unusual for patients to be told 'it will get worse before it gets better', stressing the eventual positive outcome to an unpleasant treatment.

These routines about treatment were very functional, but difficulties were encountered when treatment was not routine, when changes had to be made because the patient's condition grew worse, metastases were detected, the condition was less advanced or responded

better than originally assessed, and plans had to be altered. Changes of plan and additional treatments to new areas were potential cues to patients that their condition had worsened or that cancer had spread, so conveying a worse prognosis. The problem to be faced was how to present such treatment changes optimistically. One way was to present positive information along with the news:

"We are very pleased at how you have responded to the treatment. That swelling has gone down a lot and it would be best to give you some more to the other side just to be sure."

"That node would be best treated and you've been doing well, so we might as well begin on it as soon as possible."

When a patient's cervical cancer was thought too extensive to have the usual two caesium implants as well as radiotherapy she was informed that she would probably only have twenty fractions. However her tumour decreased in size and indicated that a caesium insertion would be feasible.

Dr. S.: "Yes, you've responded very well to treatment. We'll just carry on as we're doing and you'll have an implant at the end."

Patient: "Oh, but I thought this wouldn't be necessary. Dr. F. said I might and I might not. Seeing as I am so well I took it I wouldn't need it."

Dr. S.: "Well it would be much better if you had one, and completed the treatment. It's better to have the full course, so you can have the implant at the end rather than at the beginning when you weren't so well."

Associated with particular conditions were special tests used in assessing the extent of the disease and to plan treatment. They, like treatments, were presented in a routine manner and a positive interpretation given to results, if results were presented at all.

"It is the usual procedure to do weekly chest X-rays and if that's O.K. with you we'd like to do this."

"We want to do an X-ray to pinpoint your kidneys so that we can focus the treatment better."

"We want to see if we can get to the root of this pain you're having so we'll X-ray your back and do a special X-ray on your skull."

When test results influenced treatment schedules, for instance a falling white blood count, this was reported to patients to explain changes. However, if the test referred directly to the stage of the illness or to metastases then if the result was reported this would be in generally optimistic terms, that 'it was fine', 'nothing abnormal to be seen', 'the X-ray was satisfactory'.

In order to sustain hope even among patients who had advanced cancers and knew that their prognosis was poor, doctors attempted to shield them from the fact that active treatment of the disease had stopped by offering placebo treatment with information that though the symptoms had not abated they would not give up trying.

By giving routine information to patients who had not asked, doctors to some extent made it unnecessary for patients to ask potentially awkward questions.

"You will have been told at the General you had an ulcer at the neck of the womb."

While some patients were content with the information volunteered to them, not all of the explanations sufficed. Some patients wanted more extensive information or information in more depth while doctors assessed others as asking questions in order to be assured or reassured that they did not have cancer. Just as information volunteered to patients was routinised, so routine responses to patients' demands for information existed.

Information in Response to Patients' Demands.

Because of the need for consistency over time and between doctors, responses to patients' questions mirrored the kinds of explanations offered about diagnoses, symptoms, treatment, tests and prognosis. They were routinised as was the information volunteered, in accord

with the particular condition, extent of the illness and its treatment. Because the doctor could not be sure of what lay behind the questions asked or the patient's desire to know the facts, for he could not ask him, then the assumption prevailed that the patient did not really want to know. However, it was acknowledged that a few patients did have a real desire for information and would benefit from knowing. The problem lay in recognising these patients. Because the over-riding assumption was that patients would benefit from not knowing, it was thought better not to inform patients who wanted information than vice versa. The onus was then on patients to make clear their desire for information. This was not easy to achieve given the strength of opinion that patients may be harmed by knowing. Behaviours in the ward which were associated with patients in a state of suspiciousness were assumed to get worse should the patient be given factual information about diagnosis or prognosis. Depression, agitation, worry were interpreted as arising when patients knew more than they could cope with, and these upsets would only be worsened by additional knowledge. If patients asked therefore, they were unlikely to be told unless they had a persistency which made telling unavoidable or they displayed characteristics which were believed to be consistent with a favourable response to knowing.

Diagnosis

Patients asked two principal types of question about diagnosis. One was to ask a general question about the nature of their illness or why they were having this treatment. They also asked outright if the illness was cancer. Patients could have asked this earlier, at the time of diagnosis, but some asked while in the Department,

particularly at the end of treatment. They asked "what's been the trouble?", "What's the matter with me?", and responses were of the kind which told partial truths:

"You've had a blockage in the windpipe."

"This was an ulcer and we hope the treatment will take care of this for you."

"It's been a wart in the bladder. The treatment will get rid of that for you."

"There's some shadow on the windpipe, the pressure causes difficulty in breathing, the radiotherapy is to take away the pressure and this is working and taking it away. The treatment goes on for some time being active."

Patients asked outright whether it was cancer. 'Doctor, is this cancer?', 'Is it cancer in the bone doctor?'. These questions were usually parried:

"No, cancer isn't a word we use here, it's a shadow on the lung."

"No, it's just a softening of the bone and that's causing the pain."

Even a follow-up question by the patient when told it was not cancer 'Are you absolutely sure it's not cancer?' still resulted in denial 'Yes, there's no cancer in the bone. Everything will be all right. Don't you worry.". This denial was accompanied by optimism about the outcome.

Symptoms

Patients' symptoms were often distressing and they were anxious to learn of their relief.

A woman who had a fungating breast cancer asked at her last review session:

Patient: "Is it getting any better doctor?"

Dr. F.: "It will take some time to get better. By the time we see you at the follow-up we'll be able to tell more. It takes a long time before it shows improvement. It's not getting any worse though is it?"

Patient: "No, not any worse but I worry about it."

Dr. F.: "Well you are not to worry. Worrying won't do any good."

Doctors regularly told patients not to worry, by so doing implying it was not serious.

Patient: "I'm spitting up some blood doctor. What's the cause of that?"

Dr. F.: "Oh, that's not important in itself. Nothing to worry about really. It is an indication that something is going on and it will take a while to clear up."

Patient: "What's causing this feeling of tightness and now this swelling in my arm?"

Dr. A.: "It's coming from the swelling in your neck. The same thing is causing the swelling in your arm. But don't worry about it. The treatment will take effect and it should go down within the next two weeks."

Patient: "Will it get better doctor? Will this breathlessness get better than it is now?"

Dr. A.: "I don't see any reason for it not to get better. You just stay in bed and take it easy. Rest for today."

Patient: "But I feel so awful and everything seems to be getting worse."

Dr. A.: "Well the treatment won't be taking effect yet, give it time to work. You stay put there today and we'll see how you are tomorrow."

Symptoms were also associated with advancing disease and as such an interpretation of symptoms as spread of cancer was tantamount to a worsening prognosis.

Patient: "What is this pain now?"

Dr. H.: "It's due to a reaction after your first course."

Patient: "How can that be. That was up here (breast) and this is in my legs?"

Dr. H.: "It's how it goes through the bloodstream, it sometimes does this."

Patient: "What's going to happen then?"

Dr. H.: "Well we'll do some X-rays and other tests and plan how best to treat it. There are several things we can do and it's best to wait and see. We'll call for another opinion. It could be some venous trouble you are having."

To ask about progressing illness could imply that the patient knew the original diagnosis, but this could not be explained without encouraging openness.

Patient: "Is it the same as I had treated before?"

Dr. G.: "Yes, something like that but easily put right again."

Consistency with former typified explanations was evident in maintaining the patient's state of awareness, and in avoiding confirming cancer.

Patient: "What is it down here now? Is it a tumour?"

Dr. G.: "No, it's not a tumour. It's the glands again. Remember you had your groins treated for nodes? Well these glands extend all the way up the abdomen."

Patient: "It isn't a growth then?"

Dr. G.: "No, it's not a growth. It's glands pressing on the tubes from the bladder to the kidneys. The treatment has reduced the glands again so your waterworks will function again now."

Treatment and Tests

Again patients asked general questions "Can you tell me why I'm having all this done?" "Why do I have to have this treatment?", truthful answers to which could have conveyed either or both diagnosis and prognosis. Responses to general questions about reason for treatment were given in terms of the efficiency of having radiotherapy after surgery, "the best thing there is for this condition" as "belts and braces" and a "precautionary measure". More specific answers related to getting rid of troublesome symptoms - "to make your breathing easier", "to dry up the discharge". Some patients were anxious to know if the symptoms did not get better or should they recur, could the treatment be repeated.

Patient: "If it doesn't go away completely can it be done again? What will happen?"

Dr. M.: "Well there's no reason to assume it won't go away. Your breathing is beginning to get better already."

Patient: "If the tumour has been removed once, can it be removed again?"

Dr. H.: "Yes, it can be operated upon again but let's wait and see what the tests tell us and then we'll plan your best treatment."

Patient: "But it's been two operations now and I'm still to have this treatment."

Dr. H.: "Well sometimes these operations are tricky and to be certain we get everything we back it up with treatment here. It's too early yet to be more exact about your treatment, but it's best to have this and surgery."

When treatment was completed and patients did not get better then some answer had to be given to questions about continuing symptoms or the reason for staying in hospital. This concentrated on the time taken for treatment to be effective - "It takes a while for the treatment to work" and expected improvement of some troublesome symptom,

"We want to see how much your swallowing improves."

"Let's keep you in for a few days longer till we see how your drinking and eating progresses."

implying a hopeful outcome to what was known to be a terminal illness.

Some patients sought the results of tests. When nothing untoward had been found, then this was clearly explained to patients.

"Your scan was absolutely clear. These pains you are having must be muscular for there is certainly nothing to be seen."

Responses to questions about investigations which could have elicited diagnostic information or the occurrence of spread, were explained in terms of being 'routine'.

"It was just a routine X-ray, nothing to worry about."

"It's just a case of making sure everything is going O.K. and we're quite happy with how you are doing."

In managing questions about investigations or treatment, house officers had one tactic available to them which was denied consultants. They could truthfully say on some occasions that they did not have the information sought. Results of diagnostic tests were returned directly

to consultants and decisions regarding treatment did not involve house officers. They were able to tell patients in response to their questions

"I'm only the worker here. Your X-ray results will have gone straight downstairs so you'll have to ask Dr. S. next time. But don't worry. There's no point in sitting there worrying when there's most likely nothing to worry about."

Prognosis

During the course of the study no patient was ever heard to ask a doctor whether they were dying or how long they had to live. Questions regarding prognosis were framed in terms of repeating treatment, whether the symptoms would recur, whether there was spread. In order to maintain hope, answers implying an optimistic future had to be given, even in the face of advancing disease. Symptoms which had proven resistant to amelioration by treatment were described as "taking a long time to get better", or "it's going to be a slow business", when patients were very ill. However, when the outlook was optimistic then this was reinforced "As near as we can be certain of anything in this life, you'll have no further trouble". When prognosis was less certain then responses to patients' questions were correspondingly less optimistic, yet still attempted to convey a hopeful future, whether or not this was warranted.

"There is no point in telling patients their prognosis if they are happy. Why spoil what is left for them?"

Of course, because of the characteristics of cancer, information about prognosis was contained in what was said about tests, treatment and symptoms.

Disclosing Diagnosis

Although doctors' efforts to avoid disclosure by routine responses

to questions usually succeeded, they were occasionally pressurised into telling more than they chose by persistent questioning and demands for information. If attempts to persuade otherwise were proving to be unsuccessful then eventually the patient might be told.

Dr. J.: "You had a papilloma, it's a kind of wart."

Patient: "Yes, I was told in D4 it was a wart. But is it cancerous?"

Dr. J.: "Well it could turn nasty if it wasn't seen to now."

Patient: "What does that mean? Surely it is or it isn't. You're not telling me you're putting me through all this for nothing. I would rather know what's behind this trouble."

Dr. J.: "It is a kind of cancer, yes, but it is such an early one it's wrong to put it in that bracket. But the biopsy must have shown up some suspicion. That's why it's best to treat you right away and make sure it's nipped in the bud before it can do any damage."

This kind of disclosure was observed only occasionally on ward rounds and never observed at review clinics with consultants or senior registrars. Some patients who persistently questioned knew their diagnosis and wanted details of extent of spread. Here the doctors' assessment of the patient's current state of knowledge, together with the likely reaction to more information appeared important.

Radiographer: "Dr. A. told us that Miss M. created such a fuss at out-patients, shrieking out that he was to call it cancer and she wanted to know exactly what was what. She knows her diagnosis and he's told her that the pains are probably associated with this. We've not to try to put her off. He said she was one of those who coped by talking about it so we've to go along with her. I think they're scared she causes an uproar in the ward."

Thus patients could be given information if by doing so they would react in a more reasonable fashion than if it was absolutely denied them.

Also, while the process of making the decision to tell was not evident, so long as the patient was behaving "sensibly" and apparently had enough "intelligence" not to create a disturbance then they might

be told by the house doctor in response to questioning. Special patient attributes also contributed to the belief that the patient could be informed - those with business affairs to settle or a young family to provide for. As salient as these patient attributes however was the effect of persistent questioning on the relationship between doctor and patient. To question persistently implied that the patient was dissatisfied with the information given and so with the doctor. In order to preserve a good relationship and maintain confidence in other aspects of care, the doctor was under pressure to disclose. Such disclosures acknowledged spread of disease but were still infused with optimism.

Dr. J.: "It's a long time now since it (cancer) was first diagnosed and this trouble now is really not a bad thing. In fact, it should clear up pretty quickly after the treatment's over."

When patients asked "for the truth" or "to be blunt" as long as no counter indication to telling was present, then they might be told.

Dr. W.: "If a patient asks plain for the truth and they are sensible, then I tell them. But there's no sense in ramming cancer down their throats. If they make it clear they want to know and there's no reason not to tell them it's as well to be frank."

This frankness was asserted to occur most often when patients were first referred for treatment or at follow up at out-patients after treatment was complete. It was never observed during the study with consultants but house officers were observed to tell patients when they were persistent in their asking.

Not all patients with business affairs to settle and young families were informed. Neither were all patients who were apparently intelligent and of stable temperament. Which patient attributes other than persistent asking were most likely to result in disclosure was not discernible.

Only one patient was known to be told frankly her diagnosis

without asking for it. This woman absconded after a weekend at home, and on persuading her, through her General Practitioner, to return to hospital she was informed that she had cancer. By telling it was hoped she would realise the severity of her condition and the need to comply with treatment. Here too, however, the positive outcome of early treatment was stressed along with the unpleasant news of diagnosis.

Another patient was told that she had had cancer but that it was now cured. Her inability to swallow was attributed to 'giving up' because she believed she had cancer.

Dr. M.: "I told Mrs. S. that she did have cancer when she was here in the summer but it is completely cured now. Her oesophagoscopy showed no trace of the original disease, only some scarring and narrowing and I told her she was clear. She has it in her head she has cancer, I'm sure that's why she won't eat. I've told her she had cancer but it's been cured."

By combining disclosure of diagnosis with assurance of a positive outcome, it was hoped that the patient would overcome her inability to eat. She did not.

Disclosure, though it meant acknowledging cancer and/or details of prognosis did not extend to pronouncements of life expectancy and patients were never heard to ask this. Indeed, doctors were all able to recount experience of anticipating an early death and patients far exceeding their allotted time. To have put a time on patients' lives would have been needlessly cruel and would certainly have destroyed the hope that doctors' communications were aimed at sustaining.

In their dealings with patients, doctors were faced with a difficult problem of communication. They were motivated to avoid

disclosing information which could create trouble for the patients or for themselves. They believed that most patients had no wish to be told and would react badly to knowing. This was coupled with uncertainty over which patients would benefit from knowing, irrespective of their desire for information. This combination resulted in the adoption of practices which avoided disclosure whenever possible. Such practices were based on routines aimed at increasing the patient's uncertainty over diagnosis while implying certainty over a good outcome. Routines were usually successful in avoiding decision-making over what to tell individual patients, in maintaining consistency in what was told and in avoiding conflict between staff. Occasionally however problems arose when less experienced doctors did not apply the appropriate routines and did not conceive^d that the consultant was solely responsible for telling. At times too, the desire to avoid disclosure resulted in patients being told categorically that they did not have cancer and that cure was assured them. Exceptionally, when patients continued to demand information or when doctors tried to encourage compliance with treatment or the avoidance of disruption, disclosure would occur. On such occasions any information given was tinged with optimism and there was never the implication that treatment had come to an end.

References

1. DAVIS, F. (1960) Uncertainty in medical prognosis - clinical and functional. American Journal of Sociology, 66, 41-47.
2. McINTOSH, J. (1977) Communication and Awareness in a Cancer Ward, London, Groom-Helm, p.67.

CHAPTER 6

NURSE-PATIENT INTERACTION PATTERNS

Finding out how nurses communicated with patients was to prove more difficult than with doctors. The organisation of the department facilitated more comprehensive sampling and observation of doctor patient interactions. The sheer size and layout of the wards and numbers of nurses and patients involved resulted in a single observer being unable to know the whereabouts of or be present at several simultaneously occurring interactions. This difficulty was aggravated by the relative privacy of many nurse-patient encounters and the apparent infrequency and unpredictability of conversation about the illness. While it proved possible to be present on occasions when the illness featured in conversation, it was decided to supplement qualitative data by more structured observation methods and a quantitative analysis of nurse-patient interaction and communication.

This chapter describes patterns of nurse-patient interaction, chapter 7 deals with the verbal and activity contents of these interactions while chapter 8 shows the kind of information nurses reported about patients. Before going on to present the findings, the methods employed to provide these data are outlined.

Structured Observation - Period 1, August - October 1972.

The need for information on the processes of communication suggested that detailed information on individual patient careers should form the basis for data collection. At this time attention was given primarily though not exclusively to one four-bedded room at a time. One room containing male patients and following this one of female patients adjacent to the main ward corridor were selected. The basis of selection was to observe the first patient who was to have radical radiotherapy treatment admitted on the day observation

was to begin. Rooms adjoining the main corridor were favourable because these always contained patients with different types of cancer, with different prognoses and different levels of physical incapacity. The latter was an important variable in determining the amount of nurse-patient interaction. Characteristics of the fifteen patients observed during this time are given in Appendix II.

Observations were carried out on every week day and on one day at weekends for the duration of the 'target' patient's stay. It was known that this would be for approximately four weeks. While this provided data on all types of interaction engaged in by a small number of patients, observation of many nurse-patient interactions was facilitated. Direct observation was used so that conversation about the illness could be identified first hand within the totality of conversation.

Patients' communications with all types of hospital staff were being recorded and this necessitated accompanying the patient away from the ward, to treatment, tests, and the weekly review clinic. Time away from the ward is not included in observation time for the purposes of nurse-patient interaction.

Observation periods lasted an average 4.8 hours and were distributed through the hours worked by day staff - 7.30 a.m. until 10 p.m. Some observation was carried out during the hours worked by night nurses but it appeared that little extra would be gained. Given the limitations of a single observer, it was decided to confine observations to the hours worked by day nurses. More time was spent observing during the forenoon and afternoon when patients were more likely to have contact with all categories of staff. The hours spent observing in the ward are given at Appendix III.

The time during which individual patients and nurses were observed varied considerably. For patients this was due primarily to length of stay in the ward but also according to whether they were moved to another room, went home at weekends or left the ward to go shopping or for walks. Observation time for nurses varied according to off duty, holidays and absence as well as work allocation. The same nurses need not be assigned tasks for the patients being observed on successive days. Student nurses did not always remain for the whole of the four week observation period.

Recording Observations

All interactions between patients and nurses were recorded on the spot. Usually it was possible to hear what was said but on three occasions a nurse was asked to report the verbal content. Information about each interaction collected on the data sheet (reproduced at Appendix I) consisted of:

the interaction number for that day, numbered consecutively from 1

the identification number of the patient(s) taking part, patients being numbered consecutively from P1

the identification number of nurses taking part, nurses being numbered consecutively from N1

when the interaction began and ended and its duration if three minutes or longer

whether the interaction was initiated by nurse, patient or other.

Interactions could then be classified in a number of different ways:-

- a) whether less than three minutes or three minutes or more;
- b) whether initiated by nurse or patient;
- c) according to the number of nurses and patients taking part, and whether another category of personnel were involved.

In the latter classification five categories were devised.

These were:

| | |
|---|--------|
| one patient, one nurse | DYAD |
| one patient, more than one nurse | 1P, Ns |
| more than one patient, one nurse | Ps, 1N |
| more than one patient, more than one nurse | Ps, Ns |
| patient(s), nurse and other category. In practice this turned out to be always a doctor | PDN |

Nurse categories used were:

| | |
|-------------------|---|
| Trained Nurse | - any nurse, full or part-time having SRN, RGN or SEN qualifications. In this setting State Registered Nurses and State Enrolled Nurses were given very similar responsibilities with patients. |
| Student Nurse | - included student or pupil nurses at any stage of training |
| Nursing Auxiliary | - those holding no statutory nursing qualification and not in training for one. |

On a separate sheet were recorded

- the activities engaged in by the nurse
- the verbal content of the interaction.

Many interactions were of short duration and it was decided arbitrarily to time to the nearest minute only those interactions lasting three minutes or more. Short interactions, those lasting less than three minutes, were categorised as such and not accurately timed. Time spent by nurses in collecting equipment or leaving patients alone for more than a few seconds within an interaction was not included in interaction time but if the same nurse then resumed an interaction this was categorised as a single interaction and time was summated.

Summary of Observation Data - Period 1

Male patients observed 1.8.72 to 1.9.72

Female patients observed 19.9.72 to 13.10.72

Time Spent Observing (Observation Time)

Male patients 8040 minutes

Female patients 5580 minutes

13620 minutes

Number of Patients Observed

Male room 7 P1-7

Female room 8 P8-15

15

During this observation period were

| | <u>Male</u> | <u>Female</u> |
|--------------------------|-------------|---------------|
| Admissions | 4 | 5 |
| Discharges | 3 | 4 |
| Transfer to another room | 1 | 1 |

Number of Nurses Observed

Male room 18 nurses N1-10, 13-20

Female room 21 nurses N1-11, 13, 16, 18, 20-26

Nurses 11 and 12 while in the ward were not observed to interact with the male patients in the sample. Nurse 12 did not interact with female patients either and so they were excluded from the analysis. There is considerable overlap between the nurses observed in the two rooms.

Interactions Observed

| | | |
|---------------------------------------|-----------------|------------|
| Total number of interactions observed | male patients | 166 |
| | female patients | <u>208</u> |
| | | <u>374</u> |

Another 10 interactions in which there was no verbal exchange were excluded from this analysis.

Interactions lasting less than 3 minutes

| | | |
|-----------------|-----|----------------------------------|
| male patients | 143 | 86.1% of all male interactions |
| female patients | 161 | 77.4% of all female interactions |

Interactions lasting 3 minutes or more

| | | |
|-----------------|----|----------------------------------|
| male patients | 23 | 13.9% of all male interactions |
| female patients | 47 | 22.6% of all female interactions |

Interaction time for interactions lasting 3 minutes or more

| | |
|-----------------|---------------------------------------|
| male patients | 180 minutes, 2.2% of observation time |
| female patients | 433 minutes, 7.6% of observation time |
| | <hr/> 613 minutes <hr/> |

Structured Observation - Period 2, January - February 1974.

After the first period of observation, several more months were spent developing and testing hypotheses and gathering the appropriate data by observing nurses in a variety of situations in the ward. It had proven difficult however to obtain nurses' interpretations of their interactions with individual patients. More detail was required about nurses' interpretations in order to find out whether there was any theoretical underpinning or rationale for their practices which differed from that identified for doctors, and the extent of awareness among nurses of the reasons for engaging in such practices. A second period of structured observation was therefore conducted in which nurses were asked to report the content of their interactions.

This permitted nurses to present their ideas of what transpired, allowing them to abstract what they considered important in communication. While appreciating that complex and subtle processes may be involved in both assessment and decision making, it was felt that nurses reports

should provide some indication of the basis for their actions. Obtaining nurses reports also obviated the observer's presence when nurses interacted with patients and hence reduced the likelihood of observer effects.

Patients were not being accompanied away from the ward and interactions were not being listened to directly and so it was possible to increase the number of patients being observed at any one time to sixteen. Accordingly four adjacent four-bedded rooms in the main corridor were selected (Rooms 4-7 on Figure 1, page 52) which were the most convenient for observation from the corridor. They were also advantageous in having patients of both sexes and with a range of conditions. Patient characteristics are reported at Appendix II. As in Observation Period 1 the time spent observing was spread over six days in the week and averaged just over five hours daily. Observation times are presented at Appendix III. A trial was carried out over five days while it was ascertained that this method of recording would neither impose too great a strain or time commitment on nurses.

Recording Interactions

It was relatively easy to record interactions for sixteen patients from the corridor and the same observational data about interactions was recorded as in Period 1. Nurses were asked to report the activity engaged in if this was not directly observable as well as the verbal content of interactions as soon after the end of an interaction as was practicable. Nurses were asked "I saw you with _____. Can you tell me what you (did and) talked about?" Nurses soon began to volunteer. Not all interactions were reported however. Many were of such brief duration, lasting only a few seconds and containing a minimum of verbal exchange and their content was evident purely from observation. It would have constituted an added frustration to already

busy nurses to report them and they would have contributed little to data on communication processes. Of 966 interactions observed, verbal reports were obtained of 421 (42.3 per cent). Only 11 interactions (6.5 per cent) of all those lasting three minutes or more were not reported while for short interactions lasting less than three minutes verbal reports were obtained for 264 of the 798 observed (33.1 per cent).

Summary of Observation Data - Period 2

Observations were carried out between 22.1.74 and 17.2.74 on 23 days. Observation time amounted to 7157 minutes and applies to both male and female patients.

Number of patients observed

Male patients = 19 P22-24, 26-29, 31, 33, 35, 38-41, 45-47, 53, 55.

Female patients = 20 P17-21, 25, 30, 32, 34, 36, 37, 42-44, 48-52, 54.

P16 was discharged on the morning observation began, was not seen to interact and so was excluded.

During the observation period were

| | Male | Female |
|---|------|--------|
| Admissions | 11 | 13 |
| Discharges | 8 | 8 |
| Transfers to/from another room | - | 6 |
| Transferred to another ward in the hospital | 2 | - |

Number of nurses observed = 21 N1-3, 6-10, 26-38.

Identification numbers allocated in the first observation period were used where appropriate.

Interactions Observed

Total interactions observed -

| | | |
|-----------------|------------|--------------|
| Male patients | 351 | 36.3% |
| Female patients | <u>615</u> | <u>63.7%</u> |
| | <u>966</u> | <u>100%</u> |

Interactions lasting less than three minutes

| | | |
|-----------------|------------|---|
| Male patients | 312 | 88.9% of all male interactions |
| Female patients | <u>486</u> | <u>79.0%</u> of all female interactions |
| | <u>798</u> | |

Interactions lasting three minutes and more

| | | |
|-----------------|------------|---|
| Male patients | 39 | 11.1% of all male interactions |
| Female patients | <u>129</u> | <u>21.0%</u> of all female interactions |
| | <u>168</u> | |

Interaction time for interactions lasting three minutes or more

| | | |
|-----------------|---------------------|----------------------------------|
| Male patients | 249 minutes | 3.5% of observation time |
| Female patients | <u>1266</u> minutes | <u>17.6%</u> of observation time |
| | <u>1515</u> minutes | |

Nurse-Patient Interaction Patterns

All interactions were categorised as those lasting less than three minutes and those equal to or longer than three minutes. During Period 1, 18.7 per cent of all interactions lasted three minutes or longer, while in Period 2 this figure was 17.4 per cent. It is evident that nurses and patients were more likely to engage in many more brief contacts than sustained interaction.

Interaction rates were calculated for each patient and nurse. Interaction rate refers to the total number of interactions engaged in over the total observation period. Interaction time was also

calculated on an individual basis for nurses and patients for interactions lasting three minutes or more.

Table 1. Patients' Mean Interaction Rates and Times for Observation Periods 1 and 2

| Mean Values | Period 1 | Period 2 | Total |
|--|----------|----------|-------|
| Patient Interaction Rate for all interactions | 32.2 | 34.3 | 33.7 |
| Patient Interaction Rate for interactions <3 minutes | 25.4 | 29.1 | 28.1 |
| Patient Interaction Rate for interactions ≥3 minutes | 6.9 | 5.2 | 5.7 |
| Patient Interaction Time in mins. | 53.5 | 44.2 | 46.8 |
| Patient Percentage Interaction Time | 1.9 | 1.7 | 1.8 |

Table 1 shows that mean patient interaction rates during Periods 1 and 2 were 32.3 and 34.3 respectively. Most of these are accounted for in interactions lasting for less than 3 minutes, for which mean patient interaction rates were 25.4 and 29.1 respectively with a range 4 to 145.

For longer interactions, those lasting for 3 minutes or more, mean patient interaction rates dropped to 6.9 and 5.2 respectively with a range 1 to 41. Figures 2-5 show that only a few patients engaged in many longer interactions while the majority engaged in few. Only one of the 55 patients observed was not seen to interact at all and was excluded from further analysis.

The time during which interactions were observed amounted to 613 minutes in Period 1 and 1515 minutes in Period 2. For Period 1 this represents 4.5 per cent of observation time and 1.1 per cent of patients observed time. For Period 2 this amounts to 21.1 per cent

FIGURE 2

SOCIOGRAM SHOWING INTERACTIONS LASTING
3 MINUTES OR MORE BETWEEN MALE PATIENTS
AND NURSES - OBSERVATION PERIOD 1

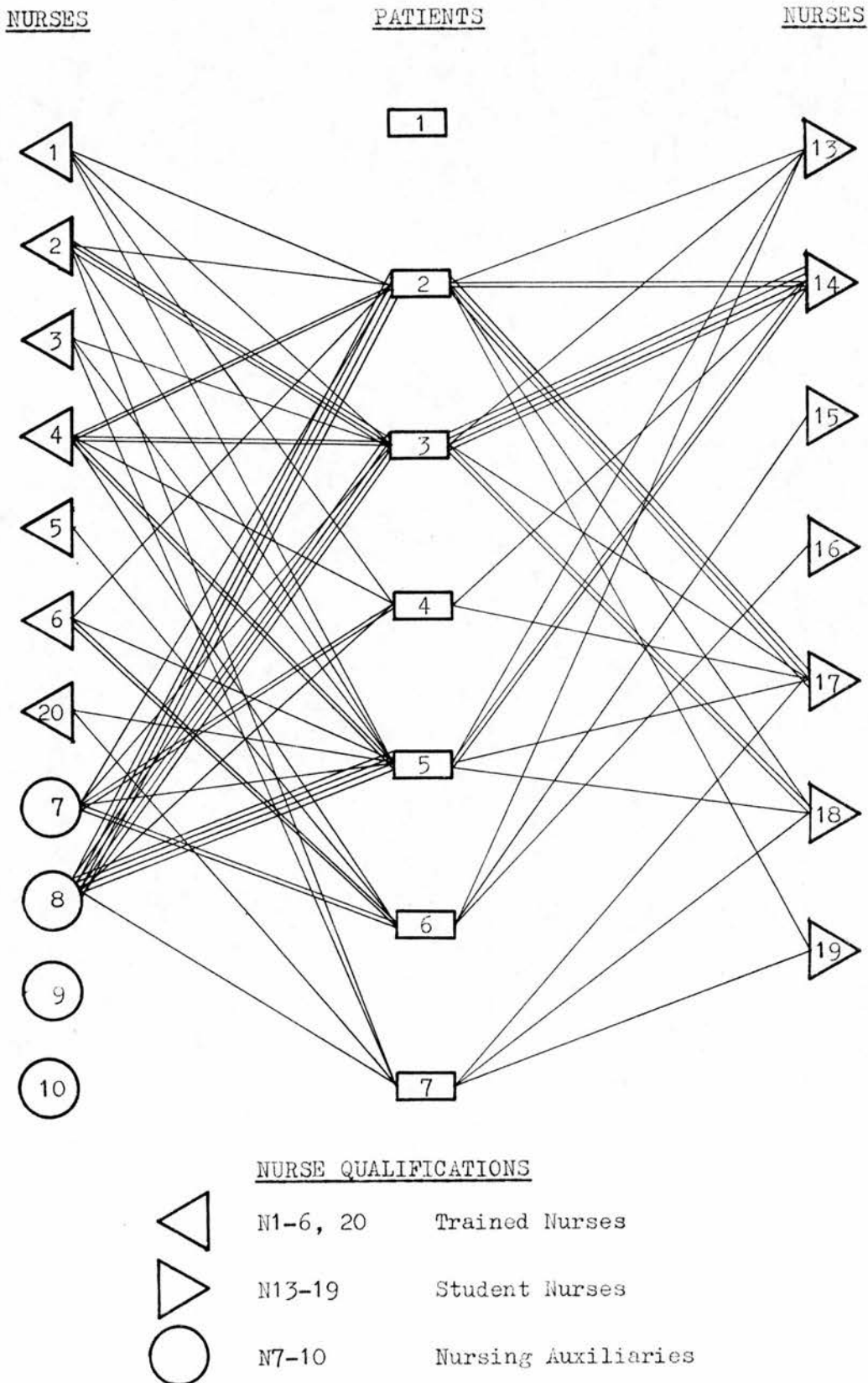
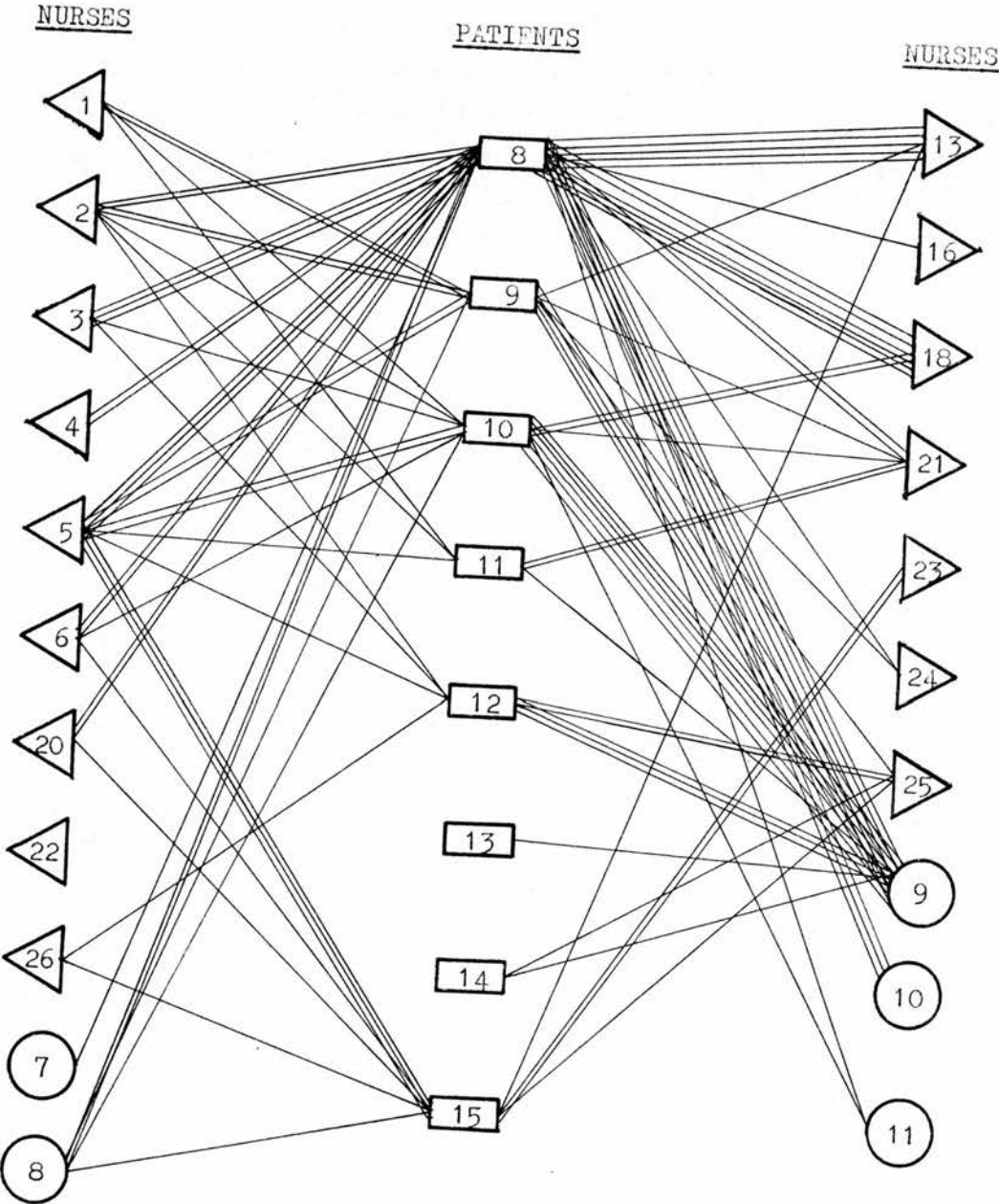


FIGURE 3

SOCIOGRAM SHOWING INTERACTIONS LASTING
3 MINUTES OR MORE BETWEEN FEMALE PATIENTS
AND NURSES - OBSERVATION PERIOD 1

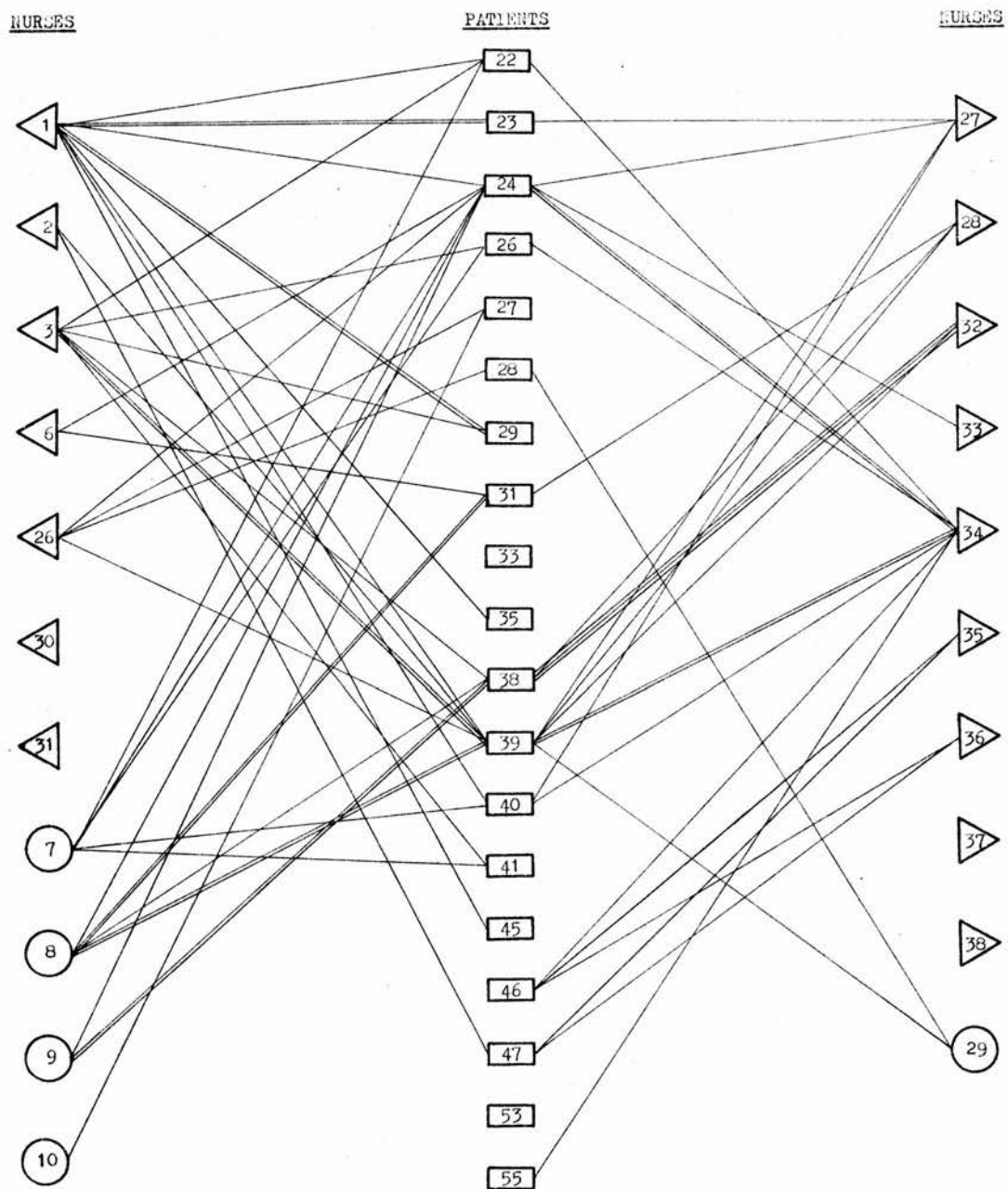


NURSE QUALIFICATIONS

- | | | |
|---|------------------------|---------------------|
| △ | N1-6, 20, 22, 26 | Trained Nurses |
| △ | N13, 16, 18, 21, 23-25 | Student Nurses |
| ○ | N7-11 | Nursing Auxiliaries |

FIGURE 4

SOCIOGRAM SHOWING INTERACTIONS LASTING
3 MINUTES OR MORE BETWEEN MALE PATIENTS
AND NURSES - OBSERVATION PERIOD 2



NURSE QUALIFICATIONS



N1-3, 6, 26, 30, 31

Trained Nurses

N27, 28, 32-38

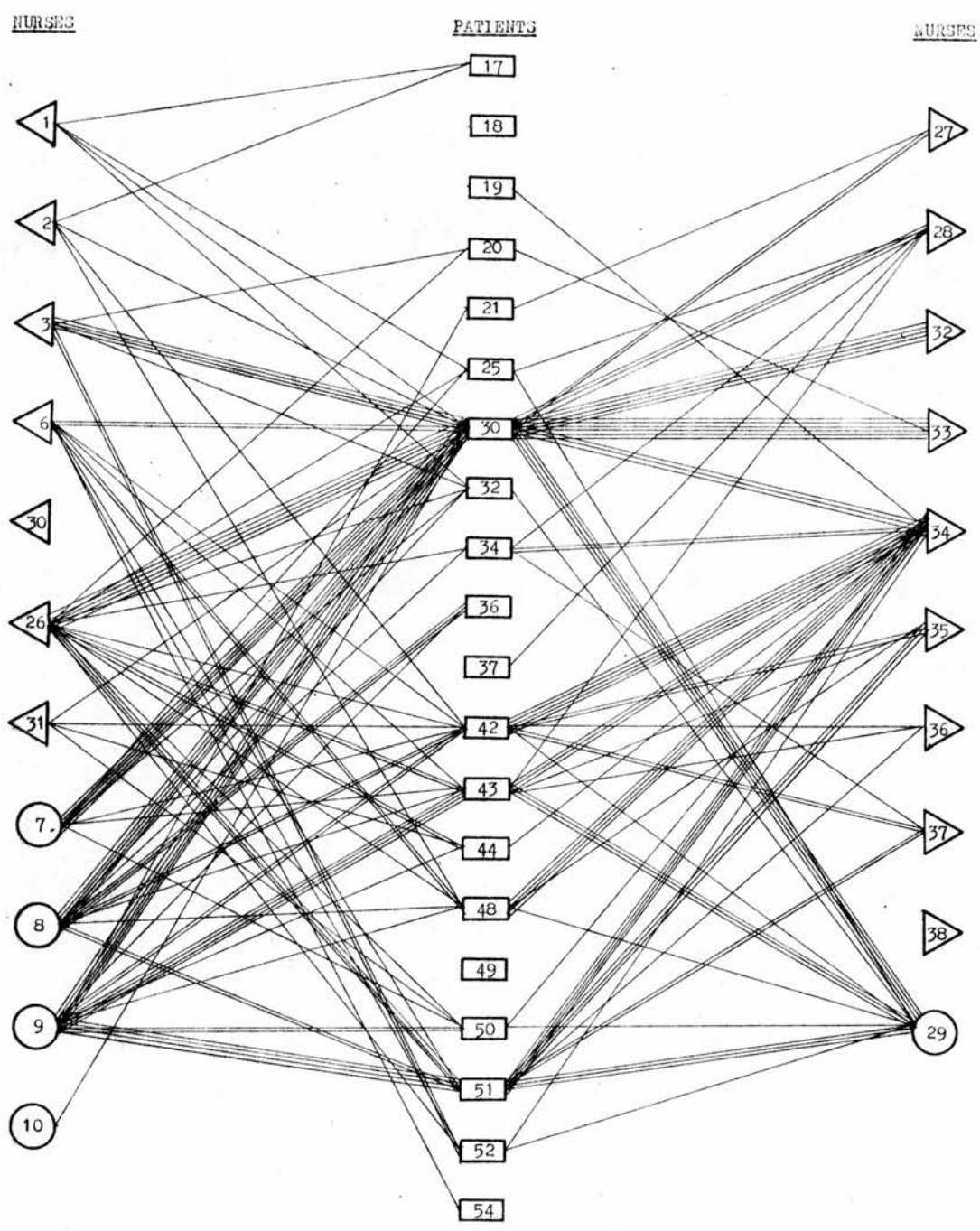
Student Nurses

N7-10, 29

Nursing Auxiliaries

FIGURE 5

SOCICGRAM SHOWING INTERACTIONS LASTING
3 MINUTES OR MORE BETWEEN FEMALE PATIENTS
AND NURSES - OBSERVATION PERIOD 2



NURSE QUALIFICATIONS

- | | | |
|---|-------------------------|---------------------|
| △ | N1, 2, 3, 6, 26, 30, 31 | Trained Nurses |
| ▽ | N27, 28, 32-38 | Student Nurses |
| ○ | N7-10, 29 | Nursing Auxiliaries |

of observation time and 1.3 per cent of patients observed time. Because several patients may be taking part in an interaction, interaction times for patients rather than interactions are slightly higher. During Period 1 interaction time for all patients was 743 minutes with a mean 53.5 minutes. For Period 2 the corresponding figures are 1722 and 44.2 minutes. Considered as a percentage of patients observed time, patients interaction time in all interactions lasting three minutes or longer represents 1.3 per cent and 1.4 per cent in Periods 1 and 2 respectively.

For individual patients, interaction time ranged from nil to 478 minutes. As a percentage of observed time this ranged from 0 to 12.5 per cent. The latter figure was obtained for a patient admitted to the ward for one day from the accident unit and subsequently transferred to a more appropriate ward. For cancer patients the highest percentage interaction time was 8.5 per cent.

Of the 54 patients observed to interact, 23 (42.6 per cent) spent more than 1 per cent of their time in interactions lasting three or more minutes. Only 7 patients (12.9 per cent) spent more than one hour with nurses, while 19 patients (35.2 per cent) spent less than 15 minutes (Tables II and III, Appendix IV).

All types and durations of interaction were included in order to present as complete a picture as possible of how nurses and patients interacted. Tables IV and V show the distribution of types of short and long interactions for Periods 1 and 2.

TABLE IV. Types of Interaction Less Than and Equal to or Longer Than Three Minutes in Period 1

| Type of Interaction | Less than 3 mins. | | 3 mins. or longer | | Total Interactions | |
|---------------------|-------------------|-------|-------------------|-------|--------------------|-------|
| | | % | | % | | % |
| Dyad | 211 | 69.4 | 18 | 25.7 | 229 | 61.2 |
| 1P Ns | 16 | 5.3 | 28 | 40.0 | 44 | 11.7 |
| Ps 1N | 29 | 9.5 | 9 | 12.9 | 38 | 10.2 |
| Ps Ns | 17 | 5.6 | 9 | 12.9 | 26 | 7.0 |
| PDN | 31 | 10.2 | 6 | 8.5 | 37 | 9.9 |
| | 304 | 100.0 | 70 | 100.0 | 374 | 100.0 |

TABLE V. Types of Interaction Less Than and Equal To or Longer Than Three Minutes in Period 2*

| Type of Interaction | Less than 3 mins. | | 3 mins. or longer | | Total Interactions | |
|---------------------|-------------------|-------|-------------------|-------|--------------------|-------|
| | | % | | % | | % |
| Dyad | 194 | 73.5 | 86 | 54.8 | 280 | 66.5 |
| 1P Ns | 21 | 8.0 | 52 | 33.2 | 73 | 17.3 |
| Ps 1N | 23 | 8.7 | 9 | 5.7 | 32 | 7.6 |
| Ps Ns | 2 | 0.7 | 6 | 3.8 | 8 | 1.9 |
| PDN | 24 | 9.1 | 4 | 2.5 | 28 | 6.7 |
| | 264 | 100.0 | 157 | 100.0 | 421 | 100.0 |

* Only interactions for which verbal reports were obtained are reported here.

Shorter interactions were more frequent in all categories except where one patient interacted with more than one nurse. When a nurse was present with the house doctor on ward rounds the time spent with individual patients generally lasted only a few seconds, only one

interaction lasting for as long as five minutes. Concern about such short contacts with patients was expressed by one ward sister:

"When you do a ward round you see a patient that's maybe depressed. You just say 'How are you?' and they answer 'Fine' so it's on to the next patient. Well that's the one that needs help more than the one that has all the complaints and worries and talks about them. I think that many of the patients are missed. They may spend a month in here and feel quite desperate about it but haven't talked about it. Maybe it's our fault for the way we do the round but to go round them all again without the doctor, that would be very difficult, there's only so much time in the day."

All patients who were in the ward at the time were seen at the ward round and this was often the only contact between patients and the nurse in charge.

Overall the preponderance of dyadic interactions is evident but is attributed to short rather than longer interactions. Table VI shows the mean values calculated for dyadic interactions in Periods 1 and 2.

TABLE VI. Patients Mean Values for Dyadic Interactions in Periods 1 and 2.

| Mean Values | Period 1 | Period 2 | Total |
|-------------------------------------|----------|----------|-------|
| Patient interaction rate, all Dyads | 15.3 | 17.0 | 16.5 |
| Patient interaction rate, <3 mins. | 14.1 | 14.7 | 14.5 |
| Patient interaction rate, >3 mins. | 1.2 | 2.3 | 1.7 |
| Patient interaction time | 7.5 | 17.2 | 14.5 |
| Patient Percentage Interaction Time | 0.21 | 0.61 | 0.5 |

The higher mean interaction times in Period 2 are due to only a few patients who show both high interaction rates and times.

Patterns of dyadic interaction lasting three minutes or more for male and female patients are shown in Figures 6-9. Bearing in mind that observation was made in rooms adjacent to the main ward corridor where interactions were likely to be more frequent than in the hostel wards, the paucity of dyadic interactions with all but a few patients is striking. Nurses stressed the importance of dyadic interaction and the absence of the doctor as the context within which patients were more likely to express their concerns,

- N1. "The patients often won't say what's troubling them in front of the doctor. They are more likely to say when they're on their own with us."
- N3. "It's when you're on your own with a patient they'll open up a bit and let you know what's on their minds."
- N13. "I think it's the face to face thing between a nurse and a patient that's important. The patient has to gain confidence in a nurse so it's when that nurse is caring for that patient you can be of most help. It's only then that a patient will be confident enough to confide how she feels, especially if they're frightened."

The very large numbers of short dyadic interactions were occasioned by the organisation of nurses' work. This was done primarily on a task allocation basis and nurses conducted a number of rounds of all patients in the ward or all patients thought to require a particular service. Dispensing medicines, distributing extra drinks, mouth washes and sputum cartons, and ascertaining menu preferences brought individual nurses into brief contact with patients. Occasionally the nurse in charge made a quick round of patients on her own in the morning if the house officer was not available and in the evening when this was often combined with an aperient round.

These brief encounters ensured that most nurses saw most patients at some time in the day. However, this apparently proved insufficient for some nurses and patients to develop any relationship. Student nurses said:

FIGURE 6

SOCIOGRAM SHOWING DYADIC INTERACTIONS
LASTING 3 MINUTES OR MORE BETWEEN MALE
PATIENTS AND NURSES - OBSERVATION PERIOD 1

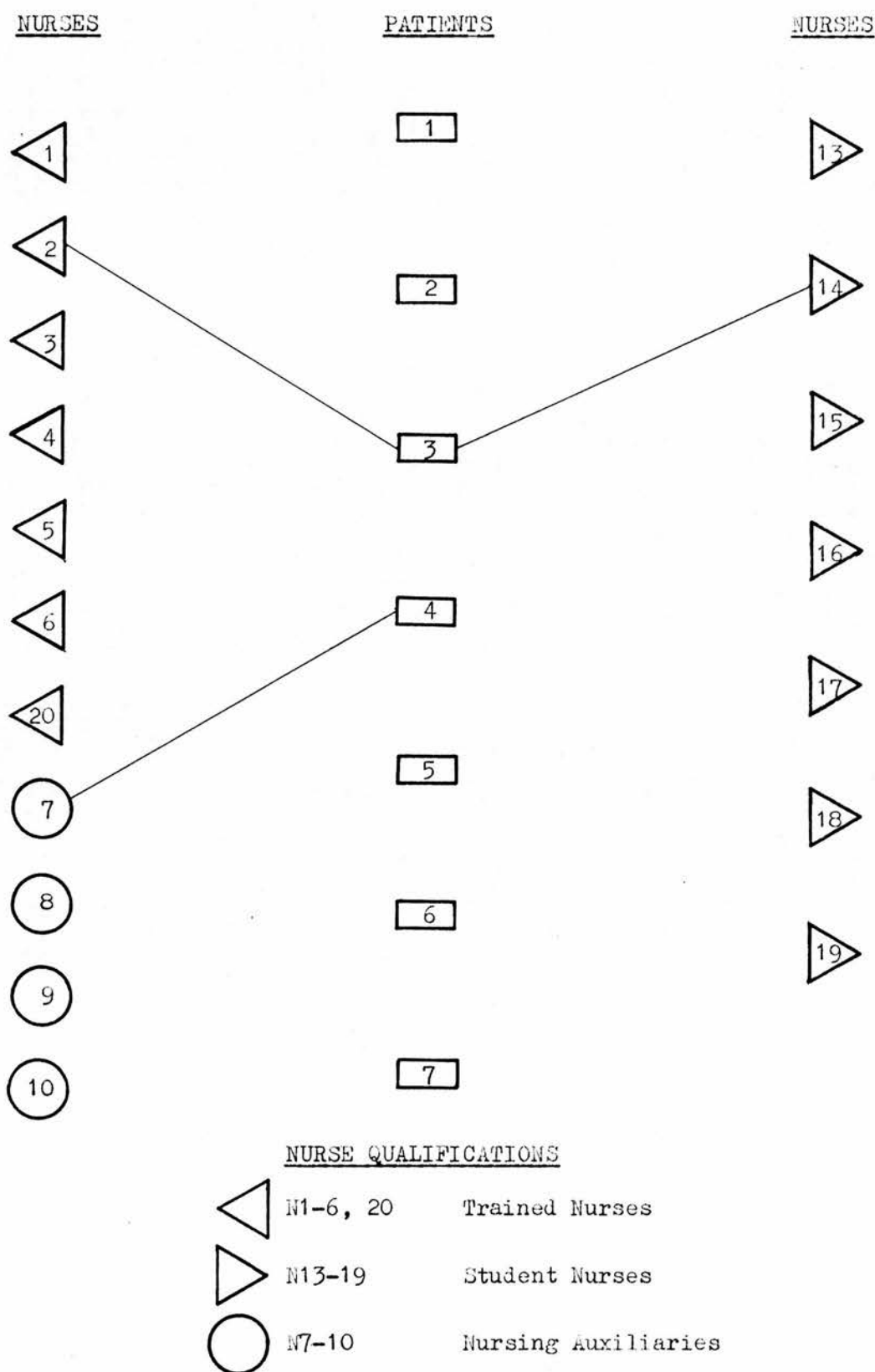
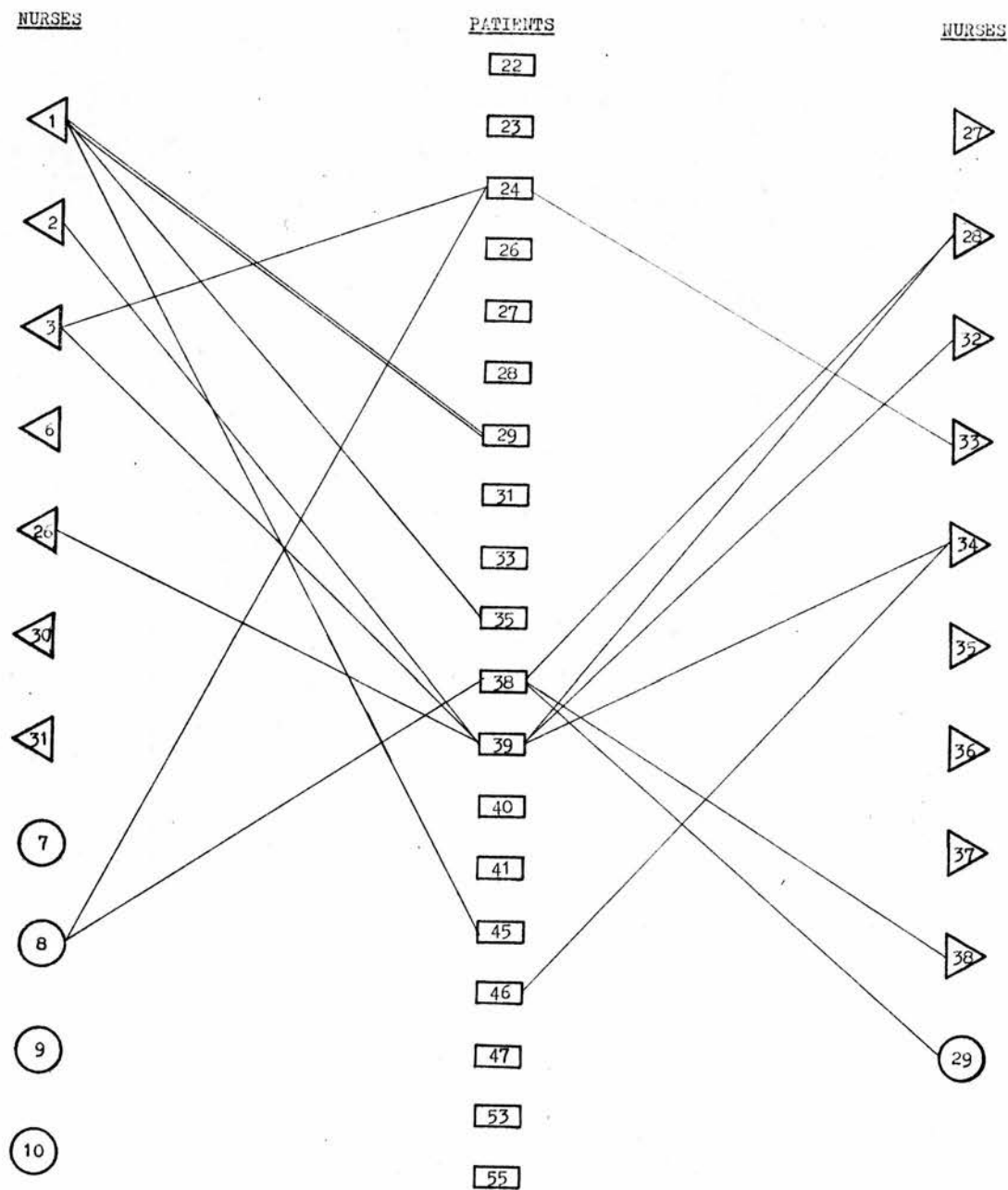


FIGURE 8

SOCIOGRAM SHOWING DYADIC INTERACTIONS LASTING
3 MINUTES OR MORE BETWEEN MALE PATIENTS
AND NURSES - OBSERVATION PERIOD 2



NURSE QUALIFICATIONS



N1-3, 6, 26, 30, 31

Trained Nurses

N27, 28, 32-38

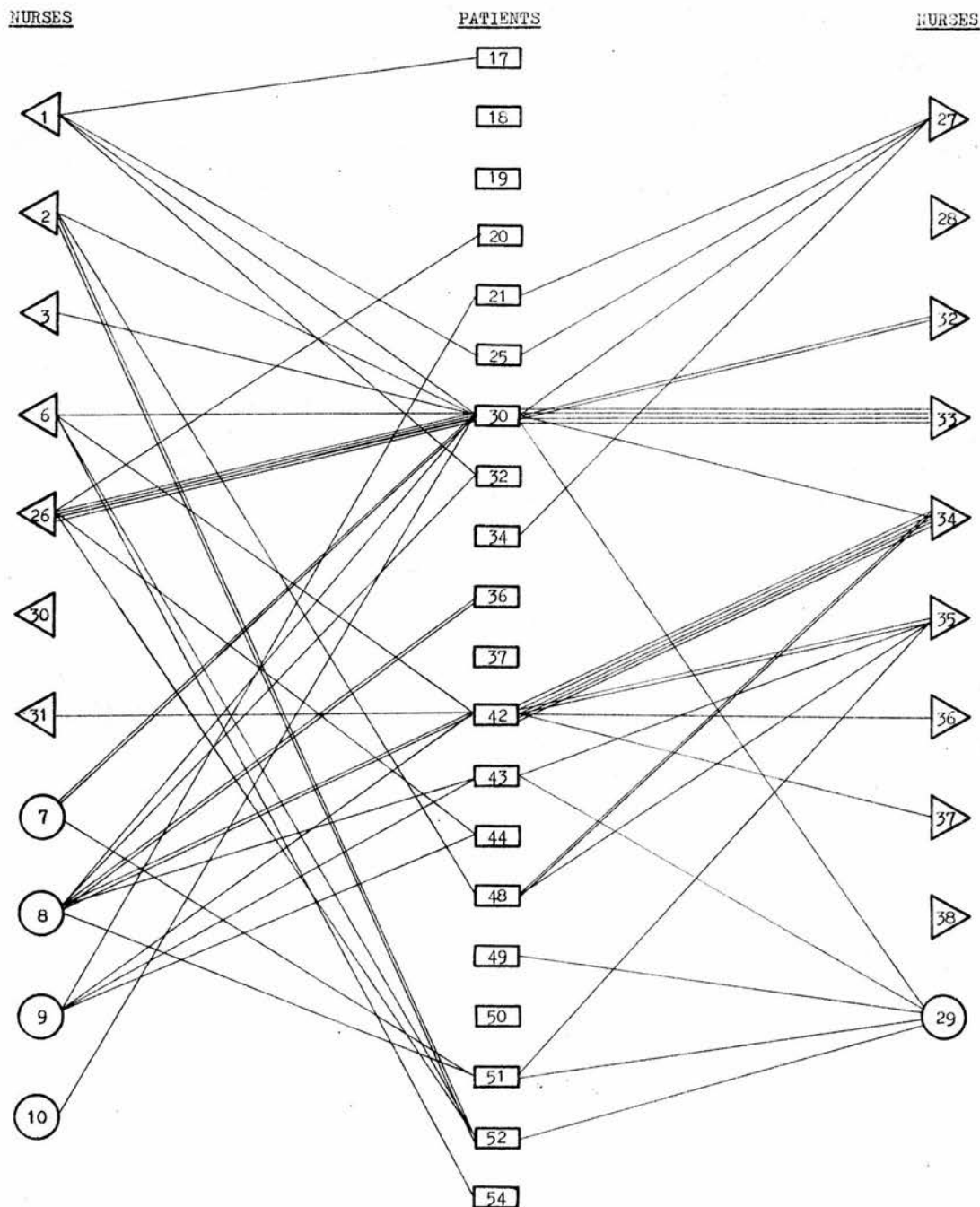
Student Nurses

N7-10, 29

Nursing Auxiliaries

FIGURE 9

SOCIOGRAM SHOWING DYADIC INTERACTIONS
LASTING 3 MINUTES OR MORE BETWEEN FEMALE
PATIENTS AND NURSES - OBSERVATION PERIOD 2



NURSE QUALIFICATIONS



N1, 2, 3, 6, 26, 30, 31

Trained Nurses

N27, 28, 32-38

Student Nurses

N7-10, 29

Nursing Auxiliaries

- N21. "I certainly haven't got to know patients here as well as in the general medical and surgical wards. The patients speak only if it's something pressing they want."
- N18. "With such a big ward it's impossible to know more than a fraction of the patients. Half the time you don't know who is a patient and who is a visitor. It's far too big, and so many patients don't need nursing."
- N17. "Here you only get to know the patients who are really ill. Somebody comes up and speaks to you and you don't realise till then that they're a patient. They don't need nursing, so many of them, so you never see them. It's the same for the trained staff. They've been here longer too, you'd think they'd get used to it. But they have the same problem."

Some patients made the same type of comment and indicated little contact with nurses or that nurses could be of help to them.

"The nurses pop in and out but I haven't needed any nursing. There're some very ill patients here and they take up all the nurses' time."

"If you're ill then you want things doing for you but most of us are not needing that kind of help. We do for ourselves so nurses aren't really necessary."

Table VII shows that the only category other than dyads which accounts for a substantial proportion of interaction time was when one patient interacted with more than one nurse. This was most often occasioned by nurses providing physical care to patients and so is unevenly distributed among patients with the same small number gaining much of the attention.

Table VII. Proportion of Time Spent in Different Types of Interaction in Observation Periods 1 and 2

| Type of Interaction | Period 1 | | Period 2 | |
|---------------------|----------|-------|----------|-------|
| | Minutes | % | Minutes | % |
| Dyad | 112 | 18.3 | 707 | 46.7 |
| 1P Ns | 369 | 60.2 | 603 | 39.7 |
| Ps, 1N | 49 | 8.0 | 68 | 4.5 |
| Ps, Ns | 54 | 8.8 | 86 | 5.7 |
| PDN | 29 | 4.7 | 51 | 3.4 |
| | 613 | 100.0 | 1515 | 100.0 |

The median values for interaction time and percentage interaction time for the whole sample are only 23 minutes and 0.78 per cent respectively. The fact that most patients spend less than 1 per cent of their time in any sustained interaction with nurses raises questions of how nurses can make continuing assessments of patients to plan care and how patients can derive help from nurses to come to terms with their illness. Not only did more than one third of patients not engage in any sustained dyadic interaction but, during Period 1, it was noted that in 207 dyads (90.4 per cent) other patients were present in the room, thus limiting aural as well as visual privacy. Nurses commented on this lack of privacy with patients as a reason for not discussing their problems.

N6. "When you go into a four-bedded room to talk to one of the patients, others immediately prick up their ears, so you don't really discuss things fully."

S/N "The big wards are easier to talk to patients in. There was more privacy because there was more going on to take patients' attention away. But not here. Whenever you go in they're all ears. I know if I was a patient I would be very wary of discussing anything that was troubling me. I would think twice about it. Everybody hears."

Some situations of privacy could be contrived, however, when nurses assisted patients to bathe for instance, but nurses did not utilise other possible quiet places in which to develop conversation with patients. Neither did they sit down with patients in the space by their beds which could have afforded closeness and a greater measure of privacy. While systematic recording of interaction was not carried out in the single side rooms, nurses were observed with patients there and were asked if the privacy made any difference. Their replies, together with observations, suggest that, in itself, the provision of privacy does not change the nature of nurses' communications:

N5. "Having a single room means that patients can tell you their bits and pieces without others overhearing but I don't think it makes much difference as far as we are concerned. You try to do your best and it really depends on the patient."

S/N "Single rooms are good for terminal cases, except they are so far away. For other patients, well they have good points and bad. The patient might be lonely but also they prefer not having others there to listen in all the time. But I don't think it makes much difference to how nurses or the house doctor deals with them."

It was not only nurses, however, who felt that privacy was lacking.

Patients commented on the fact that they had no opportunity to talk with nurses by themselves.

Patient: "I wanted to ask about what the doctor said to me downstairs but all the other women were sitting listening. We never get a chance to see a nurse by herself."

Patient: "I was wondering about this discharge that's started."

S.B. "Have you told anybody about it?"

Patient: "Well no. Downstairs* they're not really interested in that kind of thing and I've never seen a nurse on her own up here to ask about it."

Lack of contact with nurses rather than lack of privacy concerned other patients.

"Nurses here never come to talk at all. There's no warmth. When I had my operation the nurses were always taking the temperatures and popping in to do something and talking to you. But here no one ever seems to talk to you or be interested. Maybe this is a new kind of nursing."

"Unless you're ill you don't really see the nurses much. Sometimes you feel you'd like a chance to talk things over, you know. Like what happens after this treatment. Just things like that. They're all very nice but they just don't seem to have time to talk to you about yourself and that's what I feel I need. Not to dwell on things but just to settle your mind about what's going on. Nobody really explains things."

While observations were carried out in the vicinity of the patients' bed rooms time was also spent in other parts of the ward lest nurses and patients came together elsewhere. Female patients especially congregated in the sitting room and spent time in each other's rooms,

*'Downstairs' refers to the treatment floors where the patients also saw the consultants at review clinics.

a pattern of activities not observed among male patients. In the evenings both sexes watched television together. Nurses did not engage in these activities and only entered the sitting room or television room to give medicines or to ask a patient briefly if a particular problem had resolved or a dressing required changing. When a representative from a surgical appliance firm came to talk to mastectomy patients nurses were not present. The only other interactions which were observed between nurses and patients were when patients lingered in the corridor to attract a nurse's attention or went to the nurses' station. Despite the bustle of the main corridor, this appeared to afford a greater measure of privacy than in the bedrooms. Given that the great majority of interaction took place within the patients' bedrooms or in accompanying a patient to bathe, it is unlikely that significant interactions were missed.

In summary, analysis of interaction patterns shows that the large majority of interactions were of short duration and that few patients engaged in many or prolonged interactions with nurses, especially in situations affording any degree of privacy. The differences in interaction patterns relate to patients' sex and physical dependency.

Patients' Sex and Interaction Patterns

The ward layout was such that male and female rooms were intermixed and nurses worked with patients of both sexes. In Ward 1 there were always more female than male patients. Nurses typically referred to patients as 'she' when gender was irrelevant and in their interviews were more likely to refer to female patients than males.

The rooms selected for observation contained a balance of male and female patients so it was possible to test the impression that

nurses were more likely to interact with female patients and spend more time with them.

| | <u>Males</u> <u>N = 26</u> | <u>Females</u> <u>N = 28</u> |
|------------------------------|----------------------------|------------------------------|
| Total number of interactions | 556 | 873 |
| No. interactions <3 mins. | 479 | 698 |
| No. interactions ≥3 mins. | 77 | 175 |
| Interaction time | 890 | 1818 |

Inspection of crude interaction rates and times show that female patients engaged in more interactions and spent more than twice as long interacting as males. The median test was used to compare numbers of male and female patients falling above and below the median value for the total patient sample. Female patients had significantly higher interaction rates except in interactions lasting less than three minutes, higher interaction times and percentage interaction times (Tables VIII-XII, Appendix IV). For dyadic interactions, more females were above the median value than males on every comparison and all differences reached significance at $p < .02$ (Tables XIII-XVII, Appendix IV).

Nurses were aware of this imbalance. As one said:

N20. "We seem to have more contact with the women. I don't know why that is but we seem more likely to get into conversation with them."

It was observed that on the few occasions when nurses deliberately went to talk with patients when assigned work had been completed, this was with female patients. While female patients were more gregarious among themselves nurses did not join in such activities. In fact nurses were at times deliberately excluded from patients' conversations.

- N3. "You hear these women talking to each other about their mastectomies and what not, but when we go in they clam up."
- N2. "If you're working in an adjoining room sometimes you hear them talking about their operations and what's been done. Sometimes they talk about having cancer but if we go in they change the subject or just shut up completely."

Nurses were aware that males and females spent their time differently and the apparent willingness of females to engage in conversation made it easier for nurses. Because all of the nurses were female it is not possible to check whether patients and nurses of like sex would have made any difference to interaction patterns. Nurses did not report specific interactional difficulties with male patients and at no time was there any indication of interactions being avoided or encouraged because of sexual implications. Neither was it apparent that nurses were inhibited in interaction with male patients, yet they spent more time with females.

It may have been that the high interaction rates of female patients reflected their greater physical dependency which necessitated the presence of nurses and made such interaction more comfortable to sustain. A strong impression was gained that when time permitted nurses would check that incapacitated female patients were comfortable and would linger until they were called away to their next task. Being in a room with dependent patients also brought other patients into greater contact with nurses. Less time was spent in this kind of checking with male patients who, in the sample obtained, happened to be less physically incapacitated.

Patients' Physical Dependency and Interaction Patterns.

While all patients in the ward were suffering from a physical illness, some required much more in the way of physical care from nurses than others. Many patients were totally self-caring apart from

receiving medications while only a minority were totally confined to bed or chair. The majority of dependent patients were treated in the rooms in the main corridor for ease of access by nurses. The exceptions were terminally ill patients in the single rooms or women with insertions of caesium who were confined to bed for the duration of this treatment - some twenty-four to forty-eight hours. Contact with these patients was kept to a minimum in order to reduce radiation hazards to staff. Nurses were aware that much of their time was devoted to patients who demonstrated physical needs leaving little time for other patients.

N6. "By the time you've done all the baths and so on there's no time left for the other patients who look after themselves mainly. But some of that lot might be needing a different kind of help. There just isn't enough time to do what we know we should be doing. We seem to be getting more and more patients with secondaries and they take a lot of time as well as the terminal ones. The others are just left to look after themselves."

Other nurses saw their role almost completely in terms of attending to the physical needs of patients. The ward was recognised by students as a place to learn 'good basic nursing' which focused on meeting patients' needs for physical comfort. One staff nurse who had recently returned to work said:

"There's a myth about radiotherapy that there isn't much to do. When I came to see Miss P. about a job she told me this was a good starting off place for basic nursing, but most of the time was to go round and jolly the patients. They prefer a mature type of person. The truth is most of the time we have to work like fiends and this is one of the heaviest wards in the hospital, if not the heaviest. Sometimes you have all these spinal cases and they are heavy and then on top of that three or four who are very ill or dying. It's exhausting work just getting the basics done."

In order to look at the patterns of interaction with patients who were physically incapacitated, patients were classified by physical dependency according to a scheme devised by the North-Eastern Regional Hospital Board (Scotland)⁽¹⁾ as a basis for calculating nurses' work load.

This five point scale relies on patient characteristics associated with their need for nursing assistance with ambulation, toileting, bathing, feeding and other personal services which demand physical abilities. The categories are as follows:

A - BEDFAST/CHAIRFAST/TOTALLY HELPLESS

Dependent on nursing staff for all services.

B - BEDFAST/CHAIRFAST/PARTIALLY HELPLESS

Dependent on nursing staff for movement from bed to chair.

Will require assistance with toilet facilities, may require assistance with feeding and personal services.

C - BEDFAST/CHAIRFAST BUT NOT HELPLESS

Bedfast or dependent on nursing staff for movement from bed to chair. Capable of washing (either in bed or taken to wash basin), feeding self and all personal services.

D - SEMI-AMBULANT

Patient up and moving about part of day. May require assistance getting out of bed. Capable of all other services.

E - TOTALLY AMBULANT

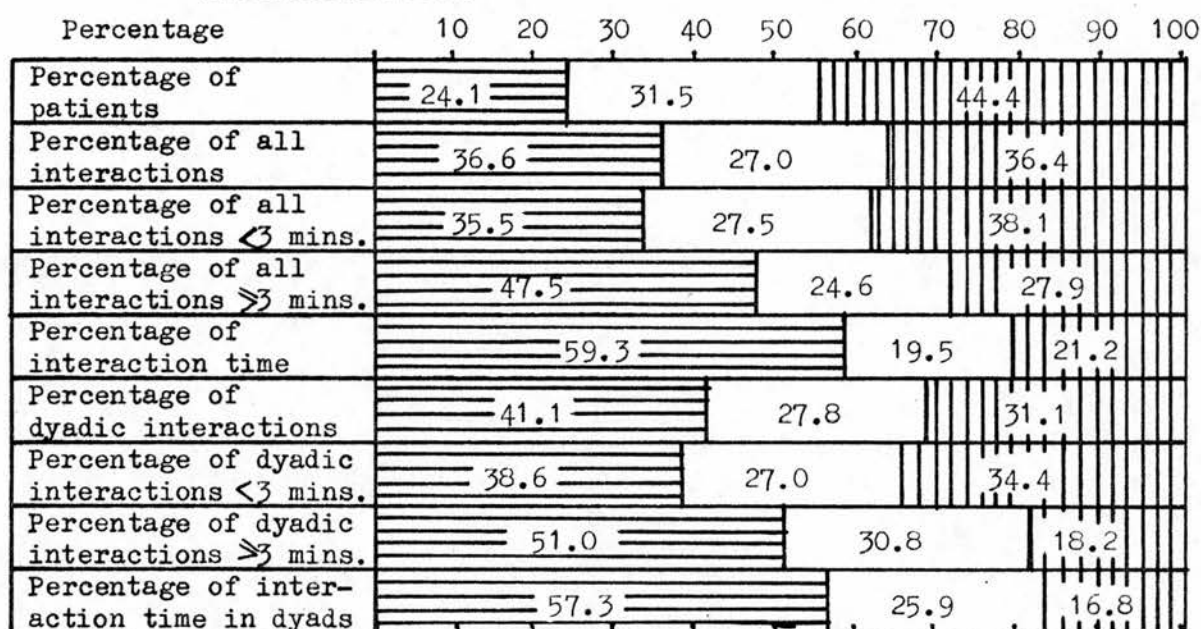
Patient up and about the ward all day.

The only amendment to this scheme was that patients requiring surgical dressings were included with category D since these involved additional nursing contact. Patients in category E had no such need for personal nursing services of this type.

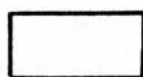
Over time patients could move from one category into another as their condition improved or deteriorated but for the purposes of classification, they were included within the most dependent category into which they fell during the period when they were observed. The first three categories each contained only small numbers and so these

were collapsed to form a single category with the unifying characteristic that, without help, patients were confined to bed or chair. Thirteen of the 54 patients (24.1 per cent) were in this most dependent ABC category, 17 (31.5 per cent) in category D and 24 (44.4 per cent) in category E. Figure 10 shows the percentage of patients in each dependency category and their corresponding share of interactions and interaction time.

Figure 10. Percentage of Patients in Physical Dependency Categories Compared with their Percentage of Interactions and Interaction Time



Category
ABC



Category
D



Category
E

Patients who were more physically dependent participated in a larger number of interactions but it was only for longer interactions that these differences were statistically significant (median test $\chi^2 = 10.38$ $p < .01$).

The ABC category patients also showed higher interaction times ($\chi^2 = 10.15$ $p < .01$) and percentage interaction times ($\chi^2 = 8.26$ $p < .02$) (Tables XVIII-XXI, Appendix IV), spending on average 115 minutes

interacting. While they represented only 24 per cent of patients, they took up 59 per cent of all interaction time and 57 per cent of interaction time in dyads. Patients who were physically independent spent correspondingly less time with nurses.

More females were in the higher dependency categories than males but the difference was not large enough to be statistically significant (Table XXII, Appendix IV). In the two categories showing physical dependency (ABC and D) there were 13 males (43.3 per cent) and 17 females (56.7 per cent).

Figure 11. Percentage of Male and Female Patients who were Physically Dependent and their Share of Interactions and Interaction Time

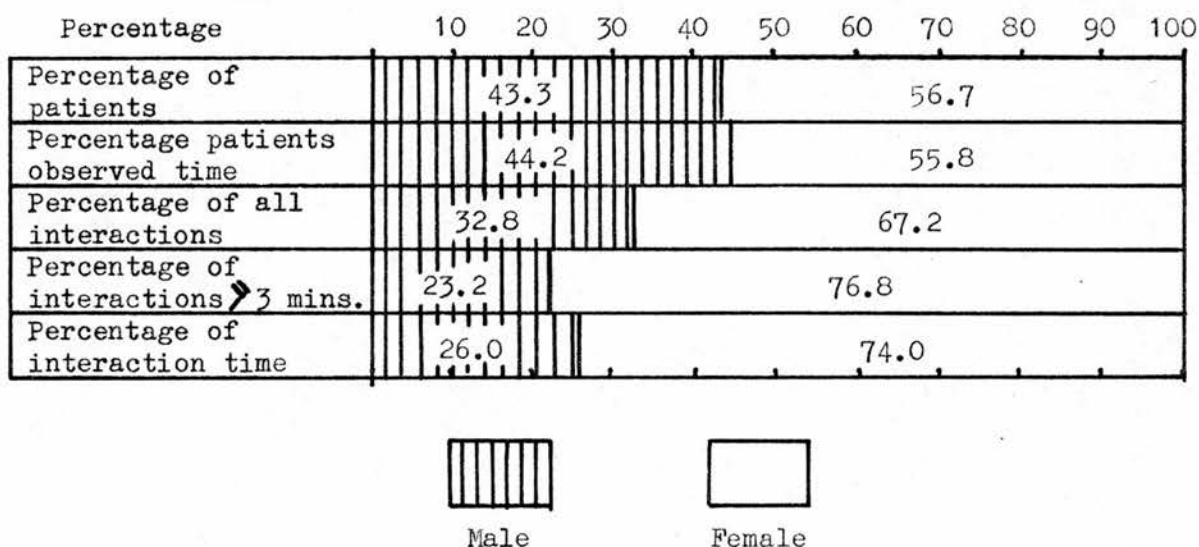


Figure 11 shows that female patients interacted more and had a higher interaction time than their numbers would have warranted had interactions been evenly distributed between the sexes within dependency categories. The combination of being female and being physically dependent resulted in higher interaction rates and times.

Attending to the physical needs of patients and getting through this work was the prime concern of nurses. It was only when work with patients with such obvious physical demands had been completed that

nurses could even contemplate attending to others. The only nurse ever observed to sit down with a patient said:

N21 "My morning's work was finished and we were all tidied up so I had time to have a natter with her."

Not having time was a real problem for the nurses who were very hard working. When there was time, however, it was difficult for nurses to readjust and to spend time with patients they felt usually received little attention. There appeared to be no convenient or valid reason for beginning an interaction. It was rare to see a nurse interacting with a patient without also doing something else for that patient. Both ward sisters said that nurses found it much easier to get into conversation with patients if something was being done for them at the same time.* Hence patients with physical needs were more likely to attract nurses to them.

Sister: "So many of the patients here are up and about. They don't need nursing care so we just say 'Good morning, how are you?' that's about all and then spend the time with the ill ones that you've got. I feel this is where we miss out. You see it's easier to go to someone in bed and start your conversation with 'How are you this morning?' 'Are you feeling any better?' 'Are you managing to drink?' then the conversation sort of flows on. Even if you incorporate it into doing something like turning down the beds. It's very different if the patient is fully dressed and rushing around with the tea trolley. But they are patients too and they need time spent with them. Not a lot of time, but more than now."

If nurses found it difficult to enter into interactions with patients not requiring physical care then it was easy to concentrate attention on patients who were obviously ill. The pressure under which nurses had to work for most of the time further added to this feeling of always having tasks to do for the incapacitated and getting routine work out of the way so as to leave time to deal with these patients or any emergency which might arise.

*This finding corroborates that by Goddard⁽²⁾ and Stockwell.⁽³⁾

For example, one patient who had been admitted part way through his treatment, and who had had psychiatric treatment a short time before, was experiencing problems both physical and mental. He had endured several sleepless nights and went to talk with the staff nurse giving out medicines from the trolley in the corridor. The nurse gradually edged away from the patient looking anxiously at the clock. Later she reported:

N6. "Poor Mr. B. he's not a well man. He's not sleeping and he's worried. He wanted to tell me something but all the time he was talking I was feeling I had to get on. There were another fifty patients waiting and if I had stayed I would never have got through the medicines and then there's all the ill ones to see to. I hate this feeling, never having time. That's where it's all wrong. That man needs help and I have to rush away."

Carrying out physical care of patients is an obvious way to facilitate learning about patients and their response to their illness. As will be seen from analysis of the contents of interactions, however, the time that nurses spent doing physical care was little used for this purpose and nurses found no other time. When time was available it was not spent with individual patients. Nurses were more likely to engage in activities away from patients or to enjoy social conversation with a group of patients. A feeling of never having time to engage patients in any prolonged conversation resulted in nurses avoiding them. Also having a large number of patients with no physical needs was contrary to nurses' expectations and at variance with how some interpreted their role. A senior student said:

N14. "This ward is different from others because so many of the patients are up and about. It's the healthiness of most of them, few need any nursing. I don't know if they need nurses here for the ones that are well. In some ways it's like a psychiatric ward, though the patients aren't ill in that way. There's less general nursing. Really I'm saying nursing here should be more communicative. As it is, it's neither one thing nor another."

It would seem that in the absence of patients requiring physical care, nurses need to learn other ways of initiating interaction. There

would also seem to be a need to consider such interactions as equally legitimate components of 'basic nursing' as is the provision of physical care. Yet, when there appears an unending series of other tasks to complete, this different frame of reference would require a major reorientation in nurses' perception, as well as in the organisation, of their work.

Nurses Interaction Patterns

Interaction rates and times for individual nurses varied considerably within each observation period. In the first, rates ranged from 0 to 46 and interaction time from 0 to 115 minutes. In the second observation period interaction rates ranged from 1 to 106 and interaction times from 0 to 299 minutes. The highest interaction time between a nurse and patient was 99 minutes and only five nurses spent more than one hour with any one patient. This was the same patient with three different nurses and three of the nurses were nursing auxiliaries.

Interaction patterns are related largely to the organisation of nurses work. Nurses were allocated to tasks rather than patients and the major part of physical care requiring prolonged contact was completed in the mornings. In successive shifts, nurses carried this out with different groups of patients. This explains why nurses interacted with many patients a few times rather than a few patients more often.

The stated rationale for encouraging that nurses should not be allocated a proportion of patients was associated with staffing policy. In the mornings it was not unusual for seven or more nurses to be on duty, some of whom were part time, arriving after the change of shift at 7.30 a.m. In the evenings, however, there were usually only three nurses and very occasionally four, of which only one was a qualified

nurse. Had nurses been assigned a small patient group it was considered impossible to make sure that in the evening a nurse familiar with each patient group would be on duty. This would have meant nurses dealing with patients with whom they were unfamiliar. Rotating assignments and task allocation were aimed at increasing nurses' knowledge of a larger number of patients. It was also stated that:

Sister: "Nurses don't like being on one end. They prefer to move and have a change of face rather than be with the same lot every day."

A less manifest function of splitting up nurses and patients was expressed by several nurses, both qualified and in training:

N21. "It's good to change wards otherwise you would get too involved. Maybe the patients would like it better having the same nurses but I wouldn't like it. You get too involved and caught up with the patients. It's hard if it's something like cancer. It might be O.K. when it's something the patient's going to get over, but with cancer it's different."

N5. "One thing you have to watch for here is not to get too fond of patients. Not to get attached to them. You can get hurt, especially when you know they're going to die."

S/N "You've got to watch out. Some patients begin to cling to you and you don't know how to deal with them. It's best not to get too attached or they begin to open up their bits and pieces. If you can't help them, especially if they're not going to get cured, well it doesn't do you or the patient any good."

While distributing attention over many patients was functional in preventing the development of close relationships between nurses and patients, some students disliked working with so many patients at any one time.

N17. "What is wrong here is in the mornings we get allocated patients needing baths but after lunch time this is all forgotten. Then we are all responsible for all the wards, somebody doing something and somebody doing something else. So you don't know what's been done for particular patients and it makes it harder to get to know the patients because you're rushing round and round all the time. You don't get the feeling that particular patients are your patients and it must be the same for patients. They won't ask if they feel they're not your patients."

N14. "Having so many it's hard to remember about them all. We're not allowed to have a note book now either. So it's bad having so many. But then we have little to do with most of them. I don't feel you can give them all they need when it's like this. We don't know the patients so we don't really talk to them. I don't mean we ignore them but we don't really get to know them. You're kind of scared because you don't know them and you get frightened in case you can't answer them. I think the system here is partly to blame but also it's because we don't know how to go about it. You don't get much chance really."

Other writers^(4,5) have commented that splitting up nurse-patient relationships is a means of nurses avoiding emotional encounters which may prove difficult to handle. While the traditional pattern of work allocation prevails together with the nurse's current conceptualisation of work, it remains difficult for nurses to develop ways of forming helping relationships with patients while coping with their own feelings. It would be an interesting research question to assess whether changing the pattern of work organisation would, in itself, change the pattern of interactions with patients requiring no physical care and the type of relationships which develop.

Nurses Qualifications and Interaction

The Radiotherapy Department was designated for nurse training purposes and so, as well as the relatively stable complement of trained staff and nursing auxiliaries, student and pupil nurses spent up to two months gaining experience of the speciality.

Qualified nurses comprised both Registered General Nurses (RGN) and State Enrolled Nurses (SEN). They were given more or less comparable status and, depending on the staffing, either could be in charge of the ward. When both were on duty, the RGN nurse always took charge, however. Only one nurse during the observation periods had had special post-basic preparation in oncological nursing, but she was present for only a few days.

Among both qualified nurses and nursing auxiliaries were part-time workers, but the hours worked by each varied from three evenings a week to just a few hours less than full time. No special distinction was drawn between full and part-time nurses in the analysis. No casual labour was employed but one volunteer came to the ward and did much the same type of work as a nursing auxiliary.

Figure 12. Comparison of Percentage of Nurses in Each Category with their Share of Interactions and Interaction Time

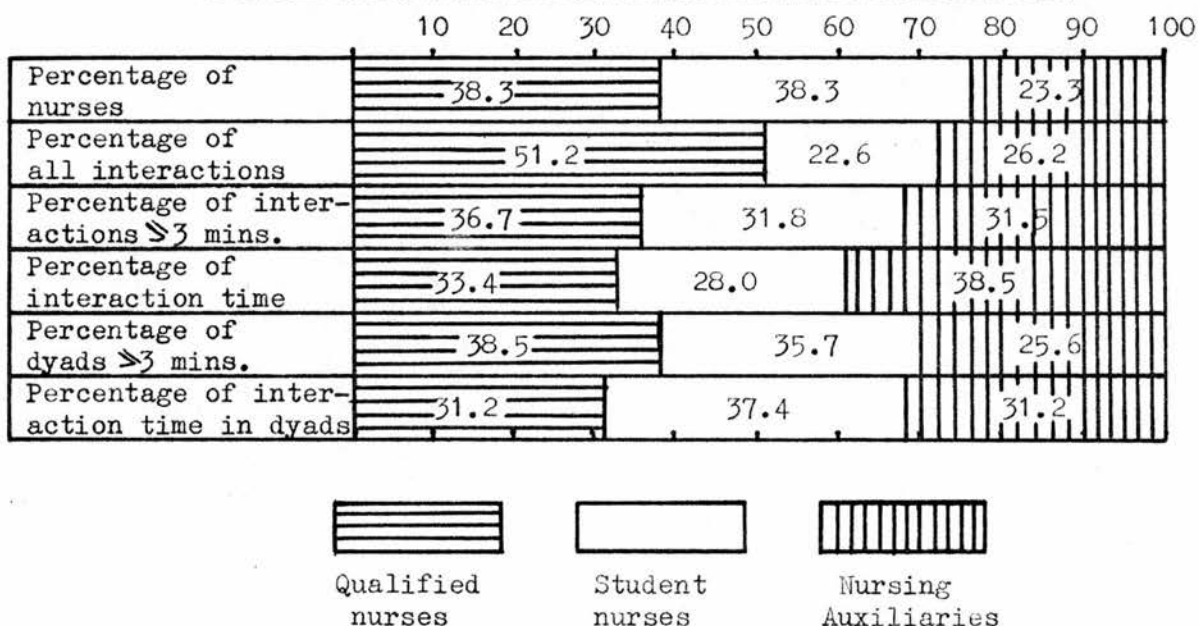


Figure 12 shows that while equal proportions of student and trained nurses were observed, trained staff were seen to engage in more interactions and spent more time with patients than did student nurses. Neither group however spent as long with patients as did nursing auxiliaries who represented 28 per cent of staff but 38 per cent of total interaction time and 31 per cent in dyads.

Within each group of nurses were wide variations. One part-time staff nurse, N26, for instance was observed to interact for 263 minutes during Period 2. This woman had recently returned to nursing and was given few of the responsibilities of her qualified colleagues.

Similarly N3, another part-time staff nurse, had consistently high interaction times in both observation periods, 113 and 153 minutes respectively, and this nurse, also, was never observed in charge on the early shift. In contrast the two most senior nurses interacted for only 24 and 43 minutes in Period 1 and 43 and 39 minutes in Period 2. The more senior the nurse the less opportunity apparently for sustained interaction. By comparison, in both observation periods the most senior nurses showed the highest interaction rates for short interactions.

This has implications for more junior nurses who look to senior staff as their role models. If they were seen to place little emphasis on interacting with patients except in the briefest and most public interactions, then future generations of nurses will be encouraged to follow this same pattern. While it was emphatically stated that students were encouraged to spend time with patients, the senior nurses did not provide a model which demonstrated that they valued or were comfortable in interactions, particularly where there was no physical task to provide a legitimate introduction. Indeed the qualified nurses as much as the students described how uncomfortable they sometimes felt and their wariness lest patients placed them on the spot by raising awkward topics or displaying strong emotion.

Senior nurses were frequently overwrought coping with the administration of such a large ward and with the procession of doctors, admissions, various technicians and the myriad of other people who passed through the ward in the course of a day and sought them out. Little time was left for contact with patients. This raises fundamental questions about the appropriate role for the most experienced nurses, the order of priorities they assigned, and which was expected of them, in enacting this role.

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CHAPTER 7

THE CONTENT OF NURSE-PATIENT INTERACTIONS

Content analysis of interactions was carried out in three ways. First reports were scored according to their complexity in an attempt to find out the extent to which nurses took into account attributes of patients and how they perceived their own contribution to the interaction. Second, reports were analysed according to activity and conversational topics. This was done in an attempt to learn something of the subject matter of importance to nurses and patients and the activities which formed the context for interactions. This type of content analysis was also performed on the observational material from the first observation period to provide a comparison with nurses' reports. Third, an analysis was performed related to the type of information which nurses regarded as relevant to their interactions. This was done in order to assess to what extent nurses used available information and knowledge to guide their interactions with patients and to identify nurses' awareness of using any theoretical principles in communication. Communication was therefore examined to find what nurses regarded as important.

During the second observation period nurses were asked to report interactions as soon as possible after their termination. It was assumed that the manner in which nurses made their reports and what they chose to report would indicate how they conceptualized interactions with patients. It was usually possible to observe or interpret the activity in which the nurse engaged but it was not possible to hear what was being said. Reports of interactions in which doctors as well as nurses participated were excluded from analysis. The remaining 396 interactions comprised 241 lasting less than three minutes and 155 lasting three minutes or longer.

The Complexity of Nurses' Reports

The manner in which interactions are analysed and classified indicates some underlying theoretical framework. Classification of reports according to their sophistication in terms of patient attributes and the nurse's contribution was aimed at finding out what nurses themselves saw as their part in the interaction and whether this related to their ideas about patients. No judgement was made about the relative value of particular interactions, only their complexity was assessed.

The classification scheme was adopted from Altschul's⁽¹⁾ study of nurse-patient interaction in psychiatric wards. This ranked reports which gave more information about the patients and/or nurses part in the interaction higher than those which added nothing to that which could have been ascertained through observation. The four point ranking system had demonstrated good inter-rater reliability.

As in the present study the reports obtained provide for only indirect judgement of the nurse's knowledge and feelings about the patient and her interpretation of the interaction. Altschul⁽²⁾ pointed out that any classification of the quality of interactions is open to a number of criticisms. Nurses, for any number of reasons, may report only a selected part of the interaction; knowing they would be asked to report they could have modified their interactions to suit or alternatively modify their report; they could have mentally rehearsed their reports making them more complete or presenting them better than might otherwise have been possible. These all apply to the present study but there is no reason to suspect that nurses would not attempt to give as favourable an impression of themselves as possible. This means that nurses may have increased their reports of interactions

which they thought would reflect a favourable picture and/or minimised reports of interactions with which they were less pleased. This would not invalidate the attempt to find out what nurses themselves consider as important and how they conceptualise interactions. In fact their selectivity may enhance this aspect of the study by highlighting the manner in which nurses feel that they should interact.

The four-point scale to categorise reports allocated scores on the following basis:

Score 1 - was given to reports which contained no information beyond that which would be available from observation alone,
e.g. "I was giving her back a rub."

"We just made her comfortable and put on her lipstick."

"She asked me to take her socks off."

Score 2 - was given to reports containing additional information about the patient,

"I gave her a pain killer, her back seems to be getting worse."

"He's had Franol for years. I gave him it just now. His bronchitis is making him more breathless than the treatment."

"She just wanted to go back to bed. She's still not able to get about much yet."

Score 3 - was given to reports which described the patient's or the nurse's part in the interaction - either the actual words spoken by either nurse or patient or the reported feelings of one or the other. Reports scored 3 therefore go beyond 1 and 2 by providing information which was not directly available from observation as well as reporting the relevance of the patient's or nurse's words or feelings.

e.g. "Mr. P. is almost finished his treatment now. He is crying and in tears with the pain. He said he had

never experienced anything like this, then he took my hand and the tears rolled down his cheeks. He's having a hard time of it."

"I went in to make her comfortable. She's better sitting up with this chest thing she's got. I told Miss N. that the doctor had thought it was fluid in her lungs rather than a chest infection and he is just giving her antibiotics as a cover."

Score 4 - was given when both the nurse's and patient's words were quoted and/or both parties' feelings were referred to.

Score 4 is given therefore when both sides of an interaction are reported together with some information about the patient. e.g. "She's been better since we moved her along here.

Just now she asked about this new medicine she's been started on. I explained to her that the mixture was part of the treatment. She said 'Is it the discs then?' I said 'Doctor hasn't said anything to the contrary'. Really he hasn't said anything about it at all so it was accurate to that extent, though it's metastases."

"I just don't know what to make of Mrs. J. She looks at you and smiles but if you ask if she's all right she just says 'Yes' although she doesn't look right - as if she wants to say something. Just now I asked if her waterworks were O.K. and she said 'Yes' and I asked about her bowels and her tummy and all she said was 'Yes, thank you'. I just don't know what to make of her. It makes me feel as if I'm not getting through to her, yet she doesn't say when she's given the

opportunity. Maybe she's just one of those folks who keep themselves to themselves."

In all interactions, the topic was known in terms of the activity engaged in and/or the conversational material. All interactions scored 2, 3 or 4 contained some information about the patient indicating that the nurse was responding to some idea or knowledge. This could be the patient's personality or social characteristics, illness, treatment or behaviour.

In addition to this, reports scored 3 and 4 contained evidence that the nurse was responding to a specific cue in the patient's communication - either a verbal one in which case the nurse reported the patient's words or an inference about the patient's feelings; or that she was aware of her own part in the interaction by reporting her own words or feelings.

Those reports scored 4 contained an account of the parts played by both nurse and patient. Altschul⁽³⁾ writes 'giving a full account of both sides of the communication indicated an awareness of the nurse's own sense of responsibility in influencing the patient's behaviour'. Thus the more fully an interaction was reported, drawing on knowledge about the patient as well as the specific cues or inferences which were available within the interaction, the higher the score.

All reports were scored twice by the author and independently by a colleague after some practice on reports obtained in the pilot study. No discrepancy was obtained among interactions scored 1. In the remaining interactions a discrepancy of 1 point occurred in 5, indicating the high reliability of the scoring system. These were resolved in agreement with the author's decision. It was not possible to score 20 reports which gave no information about the interaction.

The distribution of scores in the remaining 376 interactions was

| | |
|---------|-------|
| Score 1 | 246 |
| Score 2 | 54 |
| Score 3 | 44 |
| Score 4 | 32 |
| | <hr/> |
| | 376 |
| | <hr/> |

Reports of interactions lasting from a few seconds to over half an hour were included. Comparing interactions by length shows that for short interactions, those lasting less than three minutes, only 42 of 241 (17.4 per cent) obtained a score of more than 1 while 88 of 155 longer reports (56.8 per cent) obtained scores indicating that the nurse reported relating the interaction to some ideas about the patient. It is evident that both sides are considered in only a minority of interactions.

The Contents of Interactions

At one time studies of the work of nurses gave no particular status to activities directly involving patients compared with other activities.⁽⁴⁻⁶⁾ They also usually made no separate provision for the classification of non-physical care occurring simultaneously with some other activity. It was only when conversation with patients took place in the absence of some other activity, that it was classified alone under such general headings as 'relationships with patients',⁽⁷⁾ 'personal contact with patients',^(8,9) or 'instructions to patients'.⁽¹⁰⁾

More recently activities directly involving patients have been classified as distinct from those not involving patients.^(11,12) Hawthorne, in a study of the nurse's work in paediatric wards wrote 'care of the whole person, that is his physical and emotional well being, is essential if a high standard of nursing care is to be achieved'.⁽¹³⁾

With a greater emphasis on psychological needs, she devised a separate category of nurses work entitled 'extra care' which included social contacts with patients. 'Social contact' included any contact with the child which was not necessary to cater for his 'basic' or 'technical' nursing requirements. Hawthorne, however, still adhered to the fashion of single classification whereby, if the nurse was carrying out some 'basic' or 'technical' nursing activity, she was not also classified as engaging in 'social contact'.

Duff and Hollingshead,⁽¹⁴⁾ Altschul⁽¹⁵⁾ and Wells⁽¹⁶⁾ all provided multiple classifications of the contents of interactions in order to make a simultaneous assessment of both conversational aspects and other activities. None of the classifications of communications were totally appropriate for the present study and so a scheme was devised which would classify according to

1. Activities in which nurses were engaged with patients and conversation directly related to these tasks;
2. Social conversation;
3. Illness related conversation;
4. Social or psychological problems.

Nurse Activities

The only kind of activities of interest in the present study were those directly involving patients. Other writers interested in care directly involving patients have categorised physical care according to whether it was 'basic' or 'technical',⁽¹⁷⁻¹⁹⁾ or whether 'patient oriented', i.e. according to individual patient needs, or 'routine care' provided to all patients routinely according to policy.⁽²⁰⁾ Duff and Hollingshead⁽²¹⁾ used the scheme treatment, daily care and miscellaneous.

For the purposes of the present study the distinction between basic and technical care was maintained and activities were classified according to the scheme used in the Scottish Study.⁽²²⁾

Activities observed under the heading Basic Nursing included

| | |
|------------------------|----------------------------|
| bathing | giving bedpans and urinals |
| bed making or tidying | feeding patients |
| care of mouth | completing menu cards |
| care of hair, shaving | weighing patients |
| care of pressure areas | |

Observed under Technical Nursing were

- administering medicines and injections
- dressings
- preparing patients for tests and treatments
- taking temperature, pulse, respiration and blood pressure

In period 1, 80.4 per cent of all interactions included physical care while for reports of interactions in period 2 the figure was 66.9 per cent. Longer interactions were much more likely to be occasioned by physical care, 87.5 per cent in period 1 and 86.5 per cent in period 2 lasting for three minutes or longer, amounting to 90 per cent and 94.3 per cent respectively of interaction time. Overwhelmingly, some type of physical activity was going on when nurses interacted with patients.

Nurses themselves stressed the importance of doing things for patients to bring them into contact.

"The only way we get to know them is when we're actually doing something like bathing or getting them ready for theatre."

Brief activities like asking patients to select from the menu or giving mouthwashes and medicine initiated interactions which sometimes continued beyond completing the task. Ninety-six per cent of interactions involving giving medications however lasted for less than three minutes.

It was in longer interactions involving physical care that nurses felt they learned about patients.

"It's when we're bathing patients that they give us their wee bits and worries and then we pass them on to the trained staff to deal with them. If they don't need nursing you don't learn much about them."

Others said that they felt closer to patients if they had done things for them, but then they were faced with handling their feelings of involvement.

N5. "It's when you're bathing somebody you think 'you won't be here next year' and you wonder how she will get on when she goes home. But you can't let this kind of thing bother you too much or you would never stand it here. You've just got to push it out of your mind and treat them like ordinary patients and they were going to get on."

Doing something for patients also helped nurses overcome their awkwardness in initiating interactions.

N14. "I saw he was looking breathless and miserable and I went to ask if I could rearrange his pillows. I asked him when he was going home. He has only another two treatments, he said, and then his son will take him home. He said 'it's better to die at home'. I told him not to give up but he said it was time to give up this struggle. I've told Sister and she said she would go and have a word with him."

The privacy afforded by physical care also allowed patients to raise questions or issues of concern.

N18. "I was bathing Mrs. G. and she asked me why she had her brain X-rayed. I thought she was too insensible to know what was happening to her, she has cerebral metastases you know."

On one occasion it appeared that a patient sought a nurse to talk to her by asking for some physical attention.

N3. "Miss McD. rang for a Johnson's pad. I don't think she needed one. She told me Mr. L. (the surgeon) had been to see her today. She's a bit depressed because though he said he would put it (colostomy) back. She's depressed because her bowel has narrowed and she doesn't know if it will work out. She said she would take a pill if it didn't work out because she certainly wouldn't go through life like that. But I said they had modern techniques now and it would work out all right. She looks a bit flushed."

There is no disputing that a fundamental part of nurses' work is associated with attending to patients' physical needs. In this setting however the majority of patients evidenced no need for prolonged contact with nurses for the purpose of physical care, yet over ninety per cent of nurses' time with patients was spent in giving such care, leaving little time for other patients.

In this ward, while trained nurses most often carried out technical nursing activities, all grades were involved in basic nursing with nursing auxiliaries predominating. Summated data for observation period 1 and reported interactions in observation period 2 are given in Table XXVI.

Table XXVI. Interaction Rates and Times for Different Grades of Nurse Carrying out Physical Care

| NURSE GRADE | BASIC CARE | | | TECHNICAL CARE | | | MIXED | | |
|------------------------|--------------|-------------|--------------|----------------|-------------|--------------|--------------|-------------|--------------|
| | Interactions | | Int. Time | Interactions | | Int. Time | Interactions | | Int. Time |
| | <3 mins. | ≥3 mins. | mins. | <3 mins. | ≥3 mins. | mins. | <3 mins. | ≥3 mins. | mins. |
| Trained Nurses | 65 | 32 | 396 | 126 | 27 | 206 | 5 | 4 | 32 |
| Student Nurses | 66 | 42 | 380 | 33 | 24 | 132 | 0 | 5 | 16 |
| Nursing Auxiliaries | 76 | 74 | 744 | 14 | 7 | 63 | 0 | 1 | 3 |
| | 207 | 148 | 1520 | 173 | 58 | 401 | 5 | 10 | 51 |

What nurses spoke about with patients while they interacted is considered next.

Conversation with Patients

Interactions between nurses and patients in which no physical care was carried out are detailed in Table XXVII.

Table XXVII. Interactions Comprising Conversation Only in Periods 1 and 2

| | Interactions | | Int. Time | As a percentage of Total Interactions* Int. Time | | |
|----------|--------------|--------------|--------------|--|--------------|-------|
| | < 3 mins. | ≥ 3 mins. | mins. | < 3 mins. | ≥ 3 mins. | mins. |
| Period 1 | 58 | 8 | 59 | 21.2 | 12.5 | 9.9 |
| Period 2 | 110 | 21 | 79 | 45.6 | 13.5 | 5.7 |

*In period 2 only reported interactions are included.

Among studies conducted in non-psychiatric settings, Duff and Hollingshead⁽²³⁾ found that the ratio of talk only to talk and task oriented activities was roughly 1 to 4. Wells⁽²⁴⁾ category of personal contact with patients accounted for four per cent of nurses' activities, while Hawthorne⁽²⁵⁾ found nurses on average spent 11.4 per cent of their day in contact with children while no physical care was in progress. In the Scottish studies, services for patients which included social conversation occupied from 1.25 to 5.83 per cent of nurses total time⁽²⁶⁾ and varied from 3 minutes to 7 minutes per patient per day depending on physical dependency.⁽²⁷⁾ Goddard⁽²⁸⁾ found that student nurses spent 20 minutes per day in personal contact, staff nurses 25 minutes and ward sisters 40 minutes. These increasing periods related to seniority are probably due to doctors ward rounds being included in this category.

Because of the different ways of collecting data, no direct comparisons are possible. The small percentage of interaction time spent purely in conversational activity in the present study however, would seem to be roughly in line with the other Scottish study.

The topics raised in each interaction were categorised separately so that the full range would be noted. It was not feasible to time the parts of interactions specifically devoted to particular topics during direct observation or in nurses reports and so the duration of every interaction containing a particular subject area was included in full within that category.

Social Conversation

During the first observation period, all conversations extending beyond a few words were recorded. A wide range of social conversational topics arose, including:

- the mass media;
- personal appearance;
- visits and weekends;
- leisure activities;
- weather;
- eating and drinking;
- work and school;
- visitors, family and home;
- transport;
- other patients, hospital and staff.

These were repeated in nurses' reports.

Of the 337 interactions in Period 1, 101 (30 per cent) included some social conversation amounting to 382 minutes, 64.4 per cent of interaction time. Thirty-nine interactions comprised solely social conversation but only 7 lasted for 3 minutes or more for a total of 50 minutes (8.4 per cent of interaction time). The corresponding figures for Period 2 were: 146 interactions (36.9 per cent of the total) contained social conversation totalling 687 minutes, 49.7 per cent of interaction time. Twenty-five were purely social conversation

of which 6 lasted for 3 minutes or more. Interaction time for these amounted to 26 minutes, 1.9 per cent of interaction time.

Social topics were re-classified into three main headings, social chit-chat; talk about the patient's home, family and work; and conversation related to discharge. By far the most frequent category was the first comprising over 80 per cent of topics in observed conversations. These focused on light-hearted conversation related to the present.

Only 10 per cent of conversations touched on the patient's home circumstances, work or family. Conversations referring to home were most often related to weekend leave. It was as if the patients had no past and no future, their existence was reduced to their stay in hospital.

With particular patients, nurses returned to the same topic again and again - for instance a daily bet on horses or playing rugby. Some nurses recognised the importance of social conversation. One ward Sister said:

"It's good when the nurses have time to stop with a patient, even if it's just to look at a magazine. It shows they are taking an interest in them as people."

A staff nurse reported:

"There are some things patients just want to talk about, maybe wee things at home, maybe something they wouldn't like passed round. Mr. S, he has a young family and he knows what the score is. He said his one big regret was he would never see them growing up. He spoke away and he told me he did a reading every day in the Bible. It's this sort of thing that's important."

Nurses were careful that patients did not become too talkative however.

N8. "We are so busy. A patient begins to tell you something and you have got to get away and say 'I must bash on'. It's a problem when they're too chatty."

One nurse observed, however, that sometimes patients were withdrawn and their lack of social conversation may be indicative of some underlying cause. She reported:

- N3. "Mrs. R. had to have a psychiatrist. She was just about out the door packing her bags but nobody had noticed she was odd. This is something somebody should have spotted beforehand. In fact I think it was, but nobody did anything. She was an odd sort, a bit difficult and she didn't take an interest in anything. She just sat with her back to the other patients. Maybe we should have tried to do something about this. You see when they're in for a routine course and they're up and about you don't really have much contact. Four weeks is a jolly long time to be away from home."

While engaging in social conversation may have assisted in forming a relationship with patients, it was not evident that nurses were conscious of using it for this purpose. Social conversation however fulfilled another function. By maintaining conversation on the social level, this minimised the chance that more difficult topics might erupt. The impression gained was that nurses used social conversation primarily as a way of filling available time with patients and keeping conversation along safe lines.

Illness Related Conversation

This category was used in order to assess which aspects of the illness were discussed rather than how they were managed. Duff and Hollingshead⁽²⁹⁾ reported that between 9 and 19 per cent of interaction time with patients was devoted to discussing their illness but they did not define the category any further. Initially in the present study it was thought that a topic 'general enquiry' may be used because so many interactions were initiated by nurses saying "How are you?", "Any problems?", "All right?" to which patients gave varying responses:

"No nurse, there's no problems but I've got terrible diarrhoea." Subsequently it was the patient's response to such questions which was categorised.

Like social conversation, illness related conversation often

constituted a component of an interaction, the exception being when a senior nurse did a ward round alone and it assumed much the same characteristics as when the house officer was there. Conversation was then predominantly illness related.

In nurse-patient interactions in Observation Period 1, 39 per cent of interactions contained some conversation related to the patient's illness. Of these, 120 occurred in interactions lasting less than three minutes and 10 occurred in interactions lasting three minutes or longer. Interaction time amounted to 106 minutes, 18.1 per cent of interaction time. In nurses' reports in the second Observation Period, 240 (60.6 per cent) contained some element of conversation related to the patient's illness. Of the 240, 154 lasted for less than three minutes and 86 (35.8 per cent) occurred in interactions lasting for three minutes or longer. Interaction time in which nurses and patients discussed some aspect of illness amounted to a total of 762 minutes, 54.6 per cent of interaction time. This difference between the two periods is most likely due to the very large amounts of time nurses spent in the second with physically dependent women carrying out physical care when some aspect of the patient's physical condition was raised.

Frequency of topics raised were

| | <u>Period 1</u> | <u>Period 2</u> | <u>Total</u> |
|------------------------|-----------------|-----------------|--------------|
| diagnosis | 4 | 4 | 8 |
| prognosis | 4 | 5 | 9 |
| organic symptoms | 58 | 115 | 173 |
| treatment regime | 6 | 41 | 47 |
| tests and examinations | 5 | 4 | 9 |
| ward treatments | 7 | 8 | 15 |
| after care | 3 | 5 | 8 |
| others | <u>26</u> | <u>90</u> | <u>116</u> |

Included in 'diagnosis' were patients' questions about the cause of symptoms,

"This back pain is getting worse. What do you think is the cause of it?"

as well as frank references to cancer:

"Miss M. said Mrs. R. said it was cancer she had but she said she didn't believe her because the doctor hadn't said that and there was no history of it in her family."

Similarly, categorised under prognosis were less frank references:

"Mr. J. said he had a dull ache in his chest but he said it was getting better now. He said there must be some hope then."

Patients also frankly referred to prognosis.

"She said 'It doesn't matter. It will only make my life a little longer anyway'."

"I know I'm dying. I would like a room round the corner in the private bit; it's too noisy here."

These topics were always introduced by patients. Nurses were more likely to ask patients about their symptoms.

"I asked him about his mouth. He has a large ulcerated bit on his gum. I wanted to know if the Frador was doing any good."

"I was asking if he still had pain. He said his shoulder was still a bit sore."

Patients also reported when symptoms were troublesome.

"She told me her back and legs were very painful, and these tablets she's getting don't seem to be helping much."

"He said he didn't feel any improvement yet. I told him he wouldn't yet. It takes time to be effective."

Experienced nurses anticipated when symptoms due to treatment were likely to arise and gave advice about their control.

"I asked him how often he had to get up in the night. He said two or three times was usual for him. I explained this would get worse about half way through the treatment and go on for a while afterwards."

Sometimes patients became frustrated by repetitious advice:

"All I've heard since I came into this place is diarrhoea and 'you must keep drinking'."

Indeed the focus on symptoms was sometimes overwhelming. In Period 1, one patient who had been treated previously for carcinoma of oesophagus was readmitted with extreme weight loss and inability to swallow. Every interaction over a period of several days involved the nurse asking how much she had been able to drink and little else.

Pain was frequently the topic of short conversations, particularly bone pain from metastatic cancer when it was not controlled.

Conversations about treatment were associated with organisational details - if the patient had had it for the day, how many, when caesium would be given. Patients at this time did not ask why they were having the treatment but two asked why it was different from last time.

Nurses turned explanations of symptoms around to treatment:

N34. "She's worried about being sick so much. Maybe it's the treatment. Last night she vomited coffee ground. I said I thought that might be the treatment but she said maybe it was the Ampicillin. She's been on that since Friday morning. She's obviously worried about it."

Talk about care after the patient went home was the least frequently raised topic. It was patients who asked questions about managing at home - the amount of housework to do, when to go back to work, when to have a bath. Other studies^(30,31) have shown that it is not until patients are home that they realise that they do not have sufficient information to manage.

Other aspects of patients' physical condition were grouped together. Patients suffered a wide range of other illnesses - hypertension, thrombophlebitis, diabetes mellitus, bronchitis, urinary infections, as well as effects of being in hospital - constipation, sleep disturbance, regaining mobility after surgery. Discussion about these subjects together with nurses asking patients about fluid intake and output contributed the remainder of illness related conversation.

The implications of illness related conversation will be more fully discussed in relation to nurses' management of communication and will be considered again when patients' awareness and information seeking is discussed.

Social and Psychological Problems

This category was included in order to assess the extent to which particular patient problems of a social or psychological nature occupied interactions. In the first observation period it appeared that nurses and patients rarely discussed how patients who were aware of their diagnosis were managing or the implications of mutilating surgery. Similarly social problems which patients were experiencing - about employment prospects, obtaining life insurance or a mortgage while having cancer, having family relationship problems, a son in prison, and which were discussed among patients themselves were not discussed with nursing staff.

Observation did not suggest that nurses interacted with patients to assist with alleviation of anxiety, or to provide assistance to cope, although they may observe that a patient was experiencing difficulties. For instance, a staff nurse spontaneously reported:

N2. "Mr. N. looked very upset this morning. Nurse S. was doing his dressing and she got called away. He got very angry. In fact he looked as if he was crying or near to it. He looks to me as if he has given up all hope of getting better. Maybe he's worried about his blood - that he hasn't been cured and the low white count was an indication that something is still wrong. I'll go back and see him later on again and see what's up."

On asking if she had followed up her observation, the nurse replied:

N2. "No, I didn't find out what's bothering him. Well you know how it is. We didn't have time. And there are always other people about, so it isn't very easy."

When patients expressed how they felt there was no attempt to explore this:

"I feel I'm just dissolving away."

to which the nurse replied:

"Just like a sugar cube".

P6. "I have a sinking feeling."

N14. "Do you have a headache or something?"

P6. "No, I feel as if I'm sinking down."

N14. "A sinking feeling. Well, you try to eat this and I'll get you some water."

Conversations initiated while the nurse was with the patient in order to carry out some task may have held all sorts of meaning for the nurse and patient, and it was the observer's interpretation that they held some psychological implications relating to the patient's frame of mind.

In the second observation period nurses reports would present their interpretation of such encounters. Reports indicated that only one interaction was initiated by a nurse specifically related to how a patient was feeling.

N3. "I went to ask her if she preferred being in this room and she said it's much better here. She said it even makes the pain easier. You see she was frightened because Mrs. A. was always calling out. Mrs. A. has exactly the same as Mrs. T. and she's terminal now. I think this really frightened her. I saw she was becoming upset so we moved her along here this morning. She seems much happier now that she's down here."

On one other occasion the nurse interpreted that the patient had called for physical attention on the pretext of wanting something in order to be able to talk about her fears concerning the chance of success in surgery.

These were the only two interactions which appeared to be occasioned specifically to talk about some psychological difficulty. Nurses, however, noted that patients were experiencing difficulties and reported them:

"She felt very embarrassed."

"He was crying, he's so pathetic."

"She needs a lot of reassurance."

"She's frightened now."

Such observations about patients were made when the nurse was carrying out some physical task.

Patients' personal problems featured less than psychological difficulties in nurses' reports and only two patients were reported as discussing personal problems. One patient, on three different occasions, talked about adjusting to life with a colostomy:

N3. "She's still very uncomfortable about the colostomy. She said when she goes home she won't go out because people will know she's got it if she's smelly. She said she didn't think she would ever manage to change it by herself. She would just get a taxi to the hospital every day and get it done here."

The only other problem related to a patient forgetting where he had placed a sum of money required to pay for his lodgings. He feared being evicted if he did not pay his rent.

In Period 1, twelve interactions contained psychological problems (4.4 per cent) but only two lasted for longer than three minutes, occupying twelve minutes (2 per cent) of interaction time. In the second observation period, eleven interactions contained psychological or social problems (7.8 per cent) of which three lasted for longer than three minutes totalling 67 minutes (4.8 per cent) of interaction time.

The number of interactions and percentage of interaction time devoted to psychological and social problems was small, suggesting that nurses attached little importance to them. Yet in interviews nurses indicated that they would like to help patients more if only they knew how to go about it, and had the time.

S/N "I feel we should discuss patients' problems more. Not the illness or the side effects of treatment - we do all that now, but the patients themselves and how they are managing, whether they know about their illness, what's going to happen to them. So we can help them more. We just don't know about our patients."

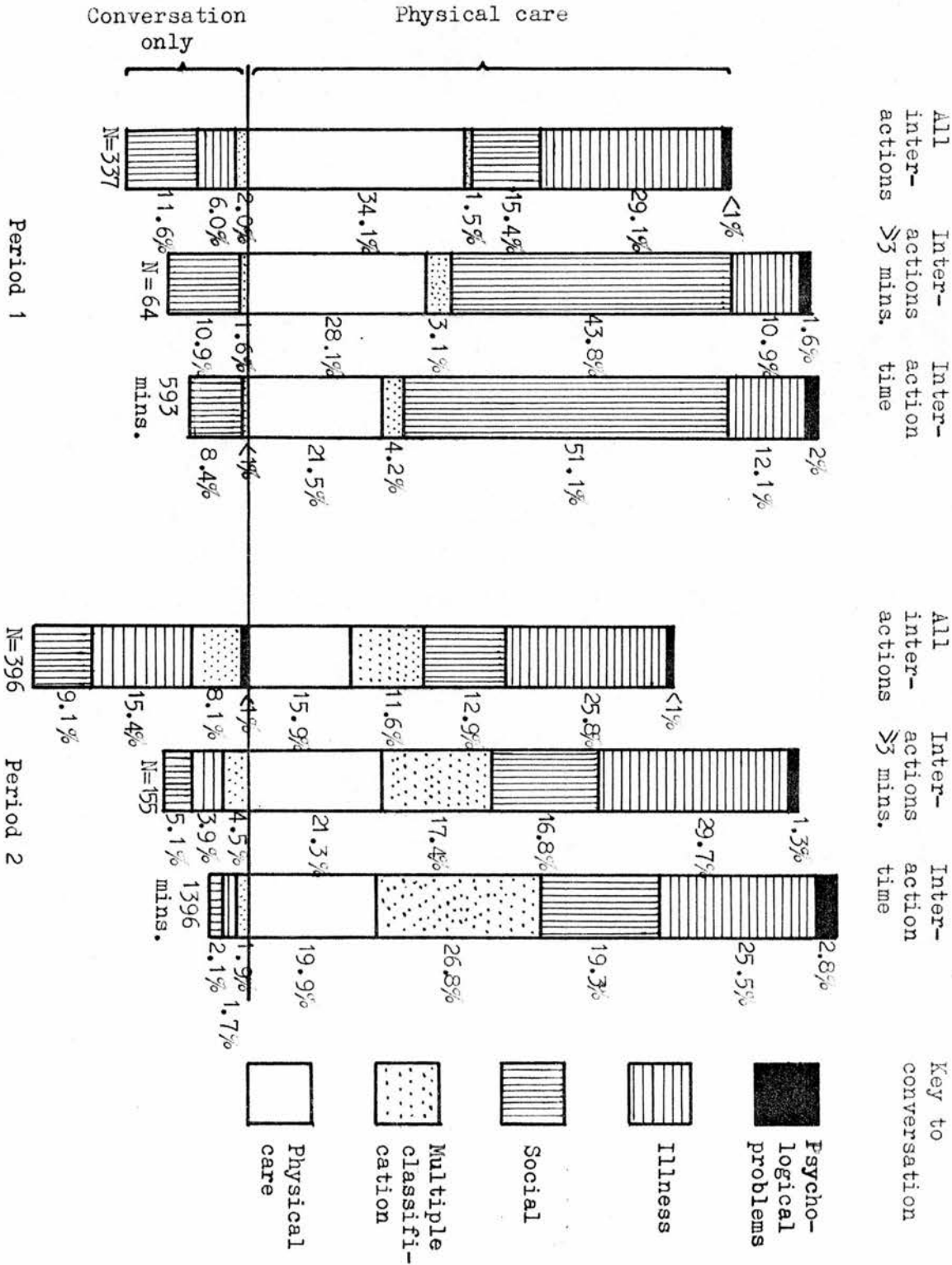
N26. "You do talk to patients but often you don't really know if they want to discuss their problems or their condition. You nurse patients but you don't really get to know what they're feeling. I think it could be a good thing to just sit and talk to patients, to try to help them over their worries. But at the same time they would maybe ask a lot of questions and I wouldn't be qualified to answer them."

Senior "If the patient feels he wants to open up about how he feels,
Student I think we should encourage this. The patient should be encouraged to bring up the topic naturally so you can carry on a conversation. But I don't find it very easy to talk. I don't know what to say."

While nurses reported that they would have liked patients to discuss their problems, they found difficulties in finding ways to facilitate this. Had patients expressed their concerns however, nurses would have experienced problems in knowing how to react for patients' benefit. As a result few patients used nurses to discuss their problems and nurses spent little time trying to ascertain the nature of patients' personal or psychological difficulties. The curt "Any problems Mr. J?" or "All right?" was singularly ineffective in ascertaining patients' difficulties and effective in limiting the kind of concerns expressed. It seemed that giving physical care or entering into social conversation with patients was necessary before patients could verbalise their problems or nurses could render any assistance to them. Even then it appeared that nurses had difficulty in establishing a helpful relationship with patients such that they were able to express what was on their minds.

Interactions were multi-classified according to the activity and conversational categories into which they fell. Overlap between categories was the rule rather than the exception. Figure 13 indicates percentages of interactions in each category for all interactions,

FIGURE 13. ACTIVITY AND CONVERSATIONAL CONTENT FOR OBSERVATION PERIODS 1 AND 2



interactions lasting three minutes or more, and interaction time for Periods 1 and 2.

In Period 1, 80.4 per cent of interactions involved physical care occupying 90.9 per cent of interaction time. In Period 2, 69.9 per cent of reported interactions involved physical care in 94.3 per cent of interaction time.

Social conversation in Period 1 occurred in 30.3 per cent of all interactions, 59.4 per cent of interactions lasting three minutes or more and in 64.4 per cent of interaction time. In Period 2 social conversation occurred in 40.1 per cent of all interactions, 42.5 per cent of those lasting three minutes or more, and 49.4 per cent of interaction time.

Illness related conversations occurred in 38.9 per cent of all interactions in Period 1, 15.6 per cent of those lasting three minutes or more and 17.0 per cent of interaction time. In Period 2, 60.7 per cent of all interactions, 54.8 per cent of those lasting three minutes or longer and 54.1 per cent of interaction time, contained illness related information.

Social of psychological problems occurred in 2.1 per cent of all interactions, 1 per cent of those lasting three minutes or longer and 2 per cent of interaction time in Period 1. In Period 2, the corresponding figures were 3.7 per cent of all interactions, 3.2 per cent of those lasting three minutes or more and 4.8 per cent of interaction time.

It must be remembered that the whole of interaction time was taken for any interaction containing any category. Without tape recording it would not have been possible to apportion time more accurately. The differences particularly in social and illness related conversations between Periods 1 and 2 may be due to the different strategies of direct recording and reporting but the patient samples differed markedly between the two periods.

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CHAPTER 8
INFORMATION ABOUT PATIENTS CONTAINED IN
REPORTS OF INTERACTIONS

Nurses were asked to report interactions in an attempt to discover what patient characteristics they regarded as important. It can be hypothesised that if nurses utilise particular patient factors to guide their communications, then this assessment should generalise across different aspects of communication. In other words, if nurses consistently assess patients or use knowledge about them as a basis for what happens in interactions, then this should be apparent in terms of both patient characteristics and contingent nursing behaviour. The question is whether this happens and, if it does, whether nurses were conscious of it sufficiently to make it explicit, or whether they operated on some intuitive level.

By asking nurses to report their interactions it was hoped to discover the kind of concepts which they regarded as relevant and whether, in their communication, they used generalised principles.

Interactions with a score of more than 1 indicated some knowledge of the patient and were amenable to this kind of analysis.

While nurses did not have access to patients' case notes, information was available to them from a wide variety of sources - from the ward synopsis of notes, the house officer's admission interview, nurses notes and reports as well as through their own observations of patients and other nurses accounts. No nursing history was recorded in writing however and nurses did not make formal patient assessments.

From the totality of information available, nurses would be selective in their reports. Some decision had to be taken about whether to prompt nurses as they rendered their accounts and whether to ask for specific types of information. It was decided that while prompting and questioning were likely to provide fuller information, this would not necessarily improve the quality of the data. To have asked questions may have led nurses to more selective reporting in accord with what they perceived as being wanted. No doubt nurses' beliefs about the observer and the purpose of the study, about what the observer wanted to hear and what she should hear influenced reports in any case. For instance one report began:

"What we spoke about isn't for your ears."

When discussing the strategy for this observation period, nurses raised the question of whether they should report 'confidential' material. When asked what kind of information this would include, replies indicated that this was primarily patients' personal problems which nurses said they did not share even with each other. Nurses were asked to indicate if an interaction contained such material, while not reporting it in detail if they regarded this inappropriate. No such reports were obtained.

Nurses may also have been selective in not reporting if they believed the information was already known to the observer or conversely may have reported information they believed relevant which the observer lacked. For instance:

N.5 "I told her not to put cream on her face. You see, they shouldn't put anything on where they've had the treatment. The consultants don't approve. She will get into trouble if she puts stuff on."

Reports were obtained repeatedly about the same patient and so nurses did not repeat information or may have avoided giving information, assuming some other nurse had done so. However events to which nurses

attached significance and which may have happened in the observer's absence were at times reported. Similarly other events were reported several times, suggesting these were of high significance to nurses.

For example,

N.6 "Her son arrived last night from Mombasa. You should have seen her, she got such a surprise. She didn't know whether to laugh or cry and she was doing both. But she said he got quite a shock when he saw she had lost so much weight."

Nurses attached a lot of importance to this surprise visit and alluded to it often although the observer had witnessed it.

While nurses provided a selective account of the information available to them, absence of information is not necessarily indicative of lack of knowledge about the patient or that knowledge was not utilised. However reports are assumed to tell something of how nurses conceptualised their interactions.

A four point scale was used based on the level of knowledge or understanding revealed in reports.

Category A was used for the most superficial knowledge, demonstrating that the nurse knew something about the patient(s) in the interaction.

Category B included some awareness of the patients' physical or mental state which was relevant to the interaction, either preceding and giving rise to it or perceived during the course of the interaction.

Category C the patient's illness, personality, mental state or social background were relevant to the interaction. Reports demonstrated the utilisation of some generalised principles.

Category D indicated some more complete grasp of theory - for instance the application of a particular coping mechanism to explain the interaction, or an understanding of psychosocial adjustment to a new body image and its relevance to the interaction.

Category A

The information imparted was not integral to the interaction. It serves as some reference to the patient or the interaction in relation to other events or knowledge. For instance:

"She's the Bingo queen. Whenever she's had treatment she's off."

"She said it wasn't as bad as she thought it would be. She's a marvellous person; keeps the others going."

"He was asking about clean clothes. He doesn't get many visitors, he lives in Boldon and he's no family."

Category B

The reports show that the nurse was aware that some aspect of the patient's physical condition, mood or behaviour were relevant in the interaction.

"He's very disappointed about not getting home."

"She's a bit worried. She hasn't passed urine since she came back from theatre."

"She's happy today. She's asking to get down to the sun lounge."

Nurses described patients using a number of psychological terms - depressed, anxious, worried, distressed, having a complex, confused. It was difficult to find out what gave rise to these assessments. Sometimes the term was coupled with a description of patient's behaviour.

"She's depressed, she's been crying. She needs a lot of reassurance."

At other times there was no indication of how the knowledge was arrived at:

"He's anxious about his treatment..."

At times patients' physical condition was reported, but this was often as background to the interaction rather than explaining it.

"She's riddled with it, she won't be having any more surgery now, only chemotherapy but even that's doubtful."

"She's terminal, she will be going to Marie Curie if they can get a bed for her."

While reporting such features indicated that nurses were aware of their relevance, it was not evident that nurses made use of it within the interaction.

Category C

Reference was made to the patient's diagnosis, or prognosis, by way of explanation of the interaction.

"She has metastatic cancer so she wouldn't be able to weight bear..."

"His bronchitis is making him more breathless than the tumour itself..."

At times the patient's mental state associated with the illness entered into descriptions of the patient which influenced the interaction.

"She's got a complex about the colostomy, she won't look at it. She feels it's dirty but..."

"I thought she was too insensible to know what was happening to her, she has cerebral metastases..."

Reports in Category C indicated that nurses utilised the knowledge they had about patients in interpreting the interaction and that generalised knowledge was involved. This was apparent when nurses drew on knowledge of the patient's history or background.

"She's asking a lot of questions. She didn't used to be like this, not last time she was in. But now she's asking about everything, and why she had to have it done..."

"He's so pathetic. His wife is in Linton Hospital and he's missing her a lot. I don't think it's the pain causing the depression as much as this..."

On only two occasions was a personality characteristic mentioned as relevant to the interaction.

"I told her what would be happening about the aspiration... She's an intelligent woman and she likes to be kept informed."

A description of the patient as 'hospitalised' was included because it appeared to be used as a personality trait which explained the patients behaviour and why the nurse acted as she did.

"She's so hospitalised... she's always asking for some special treatment. She's the kind of person you can say this kind of thing to."

The patient's state of awareness was rarely mentioned as influential.

"I said all these tests were for her own benefit and she agreed it was but then she said it will just make my life a little longer anyway. Which doesn't surprise me because she knows what she's got. I didn't say anything to her. What can you say when somebody with cancer says that?"

Category D

No reports were obtained which showed that the nurse was utilising theory in the interaction. At other times in the study nurses had indicated some theoretical explanation for the patient's behaviour.

For instance:

N.5 "She seems to be denying that she even has cancer. It's amazing that she doesn't realise. It's as if someone has drawn a blind over it and she's saying it can't be so bad because it's getting better."

This patient had a fungating breast cancer and had said that she did not think it could be cancer.

Staff "Miss G. is one of those patients who copes by asking for all the details. She knows the score and this is about all that's left now. She's been like this right from the start. So long as people are honest with her she trusts them."

All reports which revealed any knowledge of assumptions about the patient, irrespective of factual correctness, were included. The number of reports in each category were:

| | |
|------------|------------|
| Category A | 50 |
| Category B | 51 |
| Category C | 29 |
| Category D | <u>0</u> |
| | <u>130</u> |

From these reports, the basis of nurses' communication practices can be assessed. The majority of reports containing information related to the interaction indicated that nurses focussed on the immediate interaction. They stated what they perceived during the interaction - patients' mood, behaviour, physical state. When mood was mentioned, this was not generally related to fluctuations which were apparent, nor to events which may have precipitated the observed mood. The use nurses made of this information was not discernible from the reports. This mirrors what was observed at nurses' reporting sessions when nurses stated their perceptions of patients' mood without saying how they arrived at this assessment and, apart from sharing this with colleagues, the information was not apparently used as a basis for planning care.

Reports of interactions showed a far greater concern with patients' physical state, again reflecting nurses report sessions as well as the activity and conversational contents of interactions. They were more likely to report patients' symptoms however than relate this to the underlying pathology. While a range of other diagnoses were mentioned as relevant to the interaction - cardiac failure, diabetes, bronchitis, urinary tract infection - the fact that the patient was

having to adjust to cancer played an insignificant part. In a few instances the fact that the patient had metastases or a poor prognosis was mentioned but this was used as background to the interaction rather than integral to it.

Inhibition in referring to patients' condition may be related to the general tendency not to relate interactions to the patients' history. Only in one report of an interaction with a patient who had had a mastectomy for breast cancer was this fact mentioned. Its significance was not apparent from the nurse's report however and her response to the patient appeared of doubtful value.

N.30 "I was bathing her. She was a bit embarrassed. She only has one breast and she was embarrassed about it. I said there was no need, we see all kinds here."

While nurses were aware that a patient with a newly formed colostomy was having difficulty in adjusting to it, no conscious plan was devised to attempt to assist her begin to cope with this change. The apparent lack of conscious attempts to relate the patients' behaviour and mood to adjusting to their illness appears to be part of a general tendency to avoid exploration of potentially meaningful patient characteristics to explain what is happening or to use as a basis for interaction.

Analysis of contents of interactions showed that nurses rarely discussed patients' personal problems or social background with them, yet these were not usually available except directly from the patient. Reports of interactions also reinforced what had been observed, that nurses did not see it as part of their role to enter into interactions which explored how patients felt about their condition. Concentration on physical symptoms and treatment virtually excluded other individual characteristics from consideration. An example may help illustrate the point. A patient raised a problem with a nurse on two separate

occasions:

"Mrs. F. was complaining about a lump in her oesophagus. I told her the lump in her throat was due to the treatment and she accepted that all right."

Whether or not she 'accepted' it, the patient raised the problem again:

"She said last night she took a choking turn and she was afraid. She said 'I don't want to go now nurse'. I said 'How old are you?' and she said she was sixty-five. I said 'That's not old' and she said 'That's what I mean, I don't want to die yet.' I told her I didn't think she was in much danger, the choking feeling would go away once the treatment stopped."

Referral to treatment as the cause did not alleviate the patient's fears and it is doubtful whether asking the patient's age or repeating the explanation of treatment as the cause was beneficial since the patient raised the problem again with another nurse. The second nurse reported:

"She said she felt this lump, as if it was choking her. I told her to try to sleep sitting up a bit. She said she was afraid to go to sleep in case she has one of these choking attacks. She said last time she had an attack she felt as if she was dying so she's afraid to go to sleep. I said if she feels like that just to press the bell and a nurse will come. She said it was a comfort to know someone was there. She's had a fright."

On the whole, then, individual patient characteristics associated with reactions to cancer do not appear to play a significant part in interactions. As a result nurses cannot assess the patients' adaptation pattern⁽¹⁾ or the stages of adaptation suggested by Kubler-Ross⁽²⁾. Neither can they facilitate or create an environment conducive to the adjustment process.

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CHAPTER 9

NURSES' BELIEFS

The preceding three chapters have reported what was observed to happen in interactions between nurses and a small sample of patients. This chapter draws on formal interviews with nurses as well as informal conversations and presents what nurses believed about telling, their associated beliefs about patients and about their own role in communication.

It seemed important to the author to attempt to examine nurses' beliefs about patients in relation to patients' demonstrated adjustment to cancer (patients' states of awareness are discussed in Chapter 12). The literature indicates that adaptation is dynamic⁽¹⁾ and that securing adequate information is one important variable in adaptation processes.⁽²⁾ How did nurses regard information to patients as part of this adaptation process? Were patients regarded as liable to change in how they felt about the illness and in the information seeking behaviour they demonstrated? While nurses' beliefs about the needs of patients may be given as explanation of their behaviour, nurses' beliefs about their role and professional status in relation to communication were also likely to be salient.

Nurses' Views on Telling

Permanent nursing staff were aware of the prevailing medical policy of withholding diagnostic and prognostic information from patients whenever possible. In fact, they believed this happened throughout the hospital rather than just in their department. Students were less certain that any policy existed but they reported 'I get the feeling they don't tell many. The word cancer, it isn't used'.

To some extent there was agreement with medical practices, nurses advocating a conservative regime and believing that many patients have no desire to be confronted with their diagnosis. Nevertheless, they recognised that many patients would develop some degree of awareness about their diagnosis and prognosis but maintained the distinction between suspicion and certainty.

- I7 "Maybe they do (want to know) but they are scared to know. I think they all want to know deep inside. They all have a suspicion that they've got it but they don't want to be told, if you know what I mean. So long as it isn't made definite."

Thus nurses concurred with medical staff that for many patients it was better if there was no confirmation of their diagnosis.

There were no advocates of routine telling but senior nurses shared the view that more patients could be told than was now the case.

- I18 "I think there should be more patients told. Not everybody, but I think the doctors underestimate the patients. More could take it."

Thus, nurses did not always agree with how doctors were managing information to patients, particularly when patients made statements, hinted or asked questions which nurses interpreted as indicating that they knew and were seeking confirmation. The doctors responses, aimed at avoiding disclosure, were regarded as creating interactional difficulties for nurses.

- N2 "Who do they (the doctors) think they're fooling anyway? You know by the way patients ask that they know what they've got and to deny it, well it kind of makes a mockery out of them. They won't trust us again. They won't believe when we are telling them anything and that's no way to work."

So, while nurses took no part in telling, the fact that they were part of the ward team and were present when such events took place suggested to them that the doctors' refusal to be open about the illness set up greater difficulties than would an 'honest' approach.

N3 "It would have been far better to have been honest with her. At least it would have cleared the air instead of having to confront her every day knowing we've been dishonest with her."

Despite the strength of such feeling, nurses did not believe they were in a position to challenge doctors and so conflicts remained covert. On the whole however nurses supported the policy of not disclosing if there were any doubts about the patient's readiness to know.

Beliefs about Patients and Cancer

Nurses considered that some patients should be told, but, consistent with medical opinion, they believed that lay conceptions of cancer would give rise to such adverse effects that, for many patients, telling would be wrong.

I19 "Why make someone miserable by telling them they've got cancer because it's the one thing that everybody dreads. Disease is disease but cancer, well it seems like the end, like the black plague. So what's the point in telling them when the person will just lose hope of any future."

Nurses reflected the same pessimistic attitude to cancer that they expected of patients.* Half of the nurses interviewed said that they would have no desire to be told because they knew that cancer was a death sentence and knowing would create unrelievable stress. Other nurses said that they could not anticipate their own response until they actually encountered the illness. A minority said they would rather know in order to come to terms with it, but appreciated that not everyone would feel this way.

*Other studies have been consistent in showing nurses as pessimistic about cancer (3-5). A recent study by Buehler(6) in the United States suggests growing optimism based on knowledge of trends in improved treatment rather than on personal experience. The status of the data is suspect however. What nurses say to patients about cancer is not necessarily a reflection of how they feel about it.

Like doctors they could give only the most general guidelines for patients they thought could be told but had difficulty in deciding which, if any, patients would really want to know. Included among those who could be told were those with high intelligence, 'sensible people who are not likely to fly off the handle and do something silly'. Younger patients, those who had a family to provide for were assessed as prone to react badly, but nurses felt that they, together with patients who had business arrangements to settle, should be told. Also included among those who should be told were patients strongly indicating awareness and who asked. Militating against telling were any signs of mental instability or low intelligence. Nurses pointed to the difficulties of being able to assess likely response to telling - even among patients who had indicated that they wanted to know.

Some were able to quote personal experiences of disclosure believed to have precipitated both short and long term bad reactions. This happened more in surgical departments around the time of diagnosis than in Radiotherapy. These observations were highly salient for some nurses and coloured their views about telling in general. They were linked to a belief that immediate responses of a depressive nature were a bleak omen for longer term adaptation. On the other hand, patients who showed no apparent behavioural changes to knowledge of their diagnosis - who were not upset and who did not refer to it - were regarded as showing favourable adjustment. Thus patients who knew and were despondent or depressed, who nurses regarded as 'morbid' because they wanted to talk about their illness, served to reinforce nurses' beliefs that telling could be inappropriate.

This was evident when patients demonstrated a strong anxiety reaction - and, although they may have come to an awareness of their

condition without being specifically told about it - nurses regarded this as an instance when efforts should have been made to assist in the avoidance of realisation. Patients who knew they would die but who had not lost hope in the sense they still sought to postpone their death were also regarded as not being helped knowing their illness would be fatal. Like doctors, nurses advocated that some patients should know, those who could be relied upon not to react unfavourably, but no pronouncements should be made about prognosis.

I22 "I think that on the whole patients should know and it's better for them to know, to come to terms with it. But not that they are going to die and that they have got a specified time, say 12 months to live, or the early ones 5 to 10 years. I think that they should know that they have cancer and all that, but no time limit. This poses a problem though for those with a very short prognosis. I'm not sure what would be best if there's only a month or two."

Nurses therefore demonstrated much the same set of beliefs as doctors about patients. While they said that as long as a policy of non-disclosure was maintained, attitudes toward cancer were likely to remain unaltered. Still, not telling was deemed preferable to indiscriminate disclosure with the potential unleashing of adverse and potentially permanent reactions.

Nurses held differing opinions about the advisability of openness about cancer among those who knew. A minority felt that patients could be helped by expressing their concerns 'if we could only help them work through it rather than bottling it up inside them'. The majority view however was that to talk about the illness would invite trouble, patients would 'dwell on their tragedy' and 'become all morbid'. Individual differences in how patients would react to such discussion paralleled the kind of beliefs nurses held about disclosure. And the problem of uncertainty was exacerbated by not knowing for sure if the patient knew.

Nurses said that they were aware that many patients knew - but they were unable to say so with absolute certainty. They did not know what the consultants had told patients or what had been told elsewhere - at the time of diagnosis and by the general practitioner. The complexities of the issues involved was stated:

I24 "Our biggest problem here is communication. It's a nasty word but communication. Firstly with the patients. I find it difficult to communicate with them not knowing what they understand, what they've been told, what they want to know, what they would like to be told or what their relatives know and they want to happen. I think this makes life very difficult."

Faced with so many apparently unresolvable uncertainties the problem was dealt with by playing safe and avoiding communications which could precipitate openness about the illness. This was enhanced by beliefs about what was best for patients in order to maintain hope and the assumption that in the absence of definite information to the contrary patients did not know for certain their diagnosis or prognosis.

The Nurse's Role in Communication

Consistent with other studies,^(7,8) nurses maintained that imparting diagnosis and prognosis was a medical responsibility. For nurses to have told would have 'gone against the rules' imposed by both medical and nursing authorities as well as what was taught in school. One nurse went as far as to say that 'it would probably be more than my job is worth'.

While nurses at times disagreed with how doctors managed information none were willing to go against this. They had ample opportunity to do so and had the necessary information but were not prepared to shoulder such a responsibility. As well as fearing reprisals from the consultants, they were glad not to have to carry

responsibility for any adverse reactions patients may show.

I19 "It's not a nurse's job and I'm glad. We would have to bear the brunt of it if they went off or anything like that. What if I told somebody and they went and committed suicide?"

Another problem was in knowing what to say. While nurses were absolved from such responsibilities, they acknowledged that they would not know how to break news of a cancer diagnosis and of a poor prognosis and so were glad to be relieved of doing so. They were aware of such difficulties but lay some of the blame for not knowing enough about patients with their medical colleagues. They were regarded as not being sufficiently forthcoming when they reported about patients. Failure to pass on information about what they had told patients was considered just another facet of a general problem of too many doctors and too many patients and attributed to a lack of understanding by consultants of the kind of information nurses required to function effectively.

As a group nurses reinforced each other that they should not tell. Only once during the study was a staff nurse known by her colleagues to have disclosed a diagnosis.

N5 "She had no business to do that. Imagine if it was your own father she had told. It's wrong for a nurse to take on that responsibility. Who does she think she is?"

And so, nurses and doctors alike did not regard telling as the nurse's responsibility.

This did not preclude nurses being able to talk with patients about their illness so long as they already knew. Nurses regarded this as encompassed within their role. However as described above, the attendant uncertainties and beliefs about patients meant that, in fact, nurses avoided enacting this aspect of nursing care. They said it was important but it was not evident through observation and, as outlined above, nurses were able to provide reasons for not

engaging in such communications.

Maintaining Patients' Hope while Avoiding Nurses' Discomfort

Nurses described their communication with patients as maintaining hope.

I18 "What I try to do is to help the patients to feel I'm doing something for them, especially the terminal cases. What we try to do is give them encouragement and hope. There's no point in talking about having cancer with them. They would just give up and that wouldn't do any good."

While nurses were pessimistic about cancer, they believed that it was right to 'treat them as if they are going to get well again'. They felt that in a department which could be depressing, and which was believed to be regarded as such elsewhere in the hospital, they had to make special efforts to 'adopt the right attitude'. This involved encouraging patients to believe there was little to be worried about, maintaining a 'happy ward atmosphere' and assuming a countenance and disposition which would not hint at the seriousness of the patients' illness. They aimed at preventing despondency and engendering hope by presenting an optimistic picture and encouraging a belief in the transience of symptoms.

N9 "It's only natural instinct to talk about the future and how things can only get better. I know Mr. G. isn't going to live but why depress him. If you talk about their holidays and the like well, they'll feel they've got some future, something to live for. It's only natural instinct to think this way."

Such was the strength of nurses' beliefs that denying cancer and a poor prognosis was the optimum means of assisting patients to adjust to their illness that any moral dilemmas they had about their communication was resolved by persuading themselves that they were acting in the wider interests of patients. In nurses' own terms what they told patients sometimes amounted to lies or deception but this was held preferable to the envisaged alternative of endangering

any positive sentiments held by the patient about his illness or future. It was not only that nurses sought to avoid distressing patients. Their communication practices were also aimed at avoiding the trouble that distressed patients could create.

I21 "The pretence is a strain from the emotional point of view. You're pretending when you go along to a patient and there's no cure and you're talking about when you're well and that. You know quite well and you're bottling it up inside you. But you can't let on, so it's a bit of a strain. But if you look at it the other way it would make it even more of a strain if we were to let the cat out of the bag and patients knew. They would all be morbid and that would be worse than the present situation."

Nurses felt that they had neither the time nor the training to cope with such problems. However since communication practices had developed to minimise patients' expressions of distress so this reduced the problems likely to be encountered by nurses.

In summary, nurses largely shared the beliefs of medical staff about patients and endorsed their policy to the extent that many patients should not be told. They disagreed with how doctors avoided disclosure to patients whom they regarded as demonstrating an awareness of their condition and who were seeking information but did not challenge the doctors nor take it upon themselves to inform patients. Nurses regarded adjustment to cancer in fairly narrow terms and earnestly believed that avoiding reality, or at least avoiding open acknowledgement of reality, was the means by which they could most help patients. This was associated with their own feelings of helplessness and inadequacy in assisting patients to be open about their illness and fears of the consequences of such openness. The next chapter examined^S how nurses managed communication in order to avoid disclosure and maintain the ward atmosphere.

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CHAPTER 10

NURSES' MANAGEMENT OF COMMUNICATION

By the very nature of their contact with patients, nurses could not avoid being asked questions, being the focus of comments about the illness, and so, by their response, conveying information. Patients asked nurses the same kinds of questions as they asked doctors about tests, treatments and the future, direct questions as well as indirect questions about diagnosis and prognosis. Almost all nurses reported that they had on occasion been asked or had been witness to patients asking other nurses about their illness, but there were differences of opinion about the frequency of patients asking as well as about the seniority of the nurse most likely to be asked.

Perceptions of asking were associated with nurses' experiences and beliefs about the appropriateness of such events. One staff nurse for instance said:

N30 "Patients never raise their illness with me. It doesn't do any good so it's something I avoid."

This report can be contrasted with that of a first year student:

I8 "The patients know inwardly they've got something far wrong and they try in lots of ways to get round you. They try and get information out of you about what it is. Sometimes it's really terrible."

Nurses differed in their opinion of who was most likely to be the target for patients' questions.

Sister: "Well, I feel the patients consider us fair game. But the younger ones (nurses), they (patients) realise they won't have the information. They also protect students from it. Some of the older nurses seem to lay themselves more open to patients' questions."

Less senior nurses or students however believed that they were more likely to be the target for patients' questions - because they were

'closer' to patients, had more time and also they had less well developed ways of avoiding becoming entangled in questions.

Observation and discussion with nurses revealed that all grades could be asked or be the recipient of expressions about the illness and it was not obvious that differences existed in which grade was more likely to be involved. What constituted patients' asking often depended on the nurse's interpretation of the question and how much they were prepared to read into it in association with other information.

For instance:

N6 "Mrs. F. was asking me about getting home. Seemingly Dr. A. said she should get someone in to help and she asked what he meant. Do you think she's twigged? She's riddled, poor thing."

N3 "Well she knows she's got it but I don't know if she realises how far it's gone. Maybe she was just asking about organising a home help, but she could be fishing."

S.B. "What did you tell Mrs. F?"

N6 "Oh, just she'd be weak after all this so he would just be thinking of some help till she regained her strength. But I think now maybe she's trying to find something out."

Despite a variety of interpretations being possible - patients could ask about tests either to learn about their organisation or implications for their diagnosis or prognosis - it was evident that nurses managed communication to minimise patients' awareness and so help them construct and maintain a hopeful picture.

Routinisation of Communications to Prevent Awareness

Nurses said that they dealt with patients as individuals, tailoring their communication to individual needs. What nurses did in fact was to attempt to conceal cancer and a poor prognosis with the vast majority of patients. This does not mean that patients were not considered as individuals, but that the limits of individuality extended only to differences in language or disposition.

- I11 "There are no rules and everybody's different. You just learn which ones like to joke and which ones are more serious. It's something you just pick up by experience, it's not something anybody can teach you."

Nurses did not have to base their responses to patients on individual assessments. By virtue of the length of time in the ward some qualified nurses had learned the kinds of routines used by doctors and, because these avoided disclosure, nurses were free to use them. While the management of information to patients was rarely discussed with consultants, over time permanent staff had been able to observe and assimilate the doctors' techniques and knew the type of patient to which they applied.

- I19 "The doctors here rarely tell the patients. They are more likely to say it's an ulcer or a wart or a shadow on the lung depending on where it is. If it's Hodgkins or one of the lymphomas then they talk about glands swelling. It's the same with treatment. They never give a straight answer if it's been a success. They just kind of edge round it and say it takes time to be effective even if the patient's terminal. Say something like the treatment's going fine."

Student nurses as well as some less experienced staff nurses who rarely came into contact with doctors were less adept at calling such strategies into play and, as we shall see, this presented them with difficulties. Permanent staff were more able to invoke the appropriate response to patients' questions and at least one voiced the hope of consistency in what was said.

- I20 "Well we tend to use the same strategies about what to call things and the treatment and so on. My God, if we were all to go about saying something different, can you imagine? At least I hope we are all on the same wave length. Once you've been here a while you learn what to say."

Patients often asked about symptoms when nurses were attending to them and their replies invariably detracted from their severity as well as avoided allusion to the underlying pathology.

- P. "What's causing this breathlessness do you think?"

S/N "It's most likely this fluid that's collected and there may be some infection there too causing a bit of congestion."

P. "Do you think it's serious?"

S/N "Well it's serious enough to need to remove the fluid but once that's done and you've had your treatment you'll feel much better."

References to symptoms were accompanied by exhortations to the patient not to worry. In order to encourage a belief that symptoms were entirely expected and transient they were regularly attributed to treatment rather than to the illness giving rise to them. Not unnaturally patients were concerned that their symptoms would abate and asked nurses this. Rarely was immediate relief apparent and although nurses often doubted the value of treatment in this respect, but to 'attempt to jolly the patients' they had to continually stress that 'it takes time', 'you'll not see the benefits until you're home'.

While nurses presumed that doctors who organised the tests for patients would have told them why they were to have these, patients still asked about them.

P. "Why am I having this renogram thing?"

S/N "Everybody gets one, it's routine."

P. "Why do I have to have a chest X-ray now?"

S/N "They just like to keep an eye on you. Make sure all your systems are in good order before you get home."

Answers to such questions from patients could have included explanation involving their real diagnoses or search for secondaries but nurses were able to avoid such references without difficulty by employing standard routines.

On the comparatively rare occasions when patients asked a direct question about cancer nurses were able to avoid absolutely denying or confirming it by invoking uncertainty over diagnosis.

P. "This pain in my hip, it's like iron claws gripping it. Do you think it's cancer?"

Sister: "There's lots of things it could be. But let's wait till the tests are all finished. If it's bad ask for pain killers when staff comes round with the medicines."

While direct questions about cancer did not occur frequently, direct questions about prognosis were even more rare. To ask about prognosis suggested that patients knew their diagnosis. However nurses could not confirm this or take the patients' question seriously without risking disclosure. Tactics had to be used to detract from the serious nature of comments by patients who felt that they were not going to get well again.

P. "I don't think this treatment's going to do any good. It's just a matter of time now."

S/N "That's no way to talk. You'll be fit as a fiddle in no time at all. This treatment makes you feel flat. That's not unusual."

While senior nurses were often able to make some kind of neutral or routine response to patients' questions, like the house doctor they were also able to use the excuse of not having access to test results, case notes or X-rays although the information sought was usually available to them. Pleading ignorance was judged preferable to risking disclosure by attempting some kind of 'factual' answer and so even staff nurses and sisters resorted to it.

I17 "Probably they will turn round and say funny nurse that. But what's best? To let them think you're some kind of a nut or to go and put your foot in it?"

It was when nurses were faced with less easily avoided questions, direct questions about diagnosis, that they were more likely to refer patients to their consultant. Otherwise, because they had techniques for doing so at their disposal, senior nurses were equipped to handle most of the patients' questions and with sufficient confidence to feel they would not contradict what the patient had been told elsewhere.

If patients persisted in questioning however then referral was more likely.

P. "Nurse, do you think I'll get any better?"

S/N "Oh yes, the treatment will begin to have an effect in a day or two. It takes time but you'll find your breathing easier."

P. "No, I mean really better, cured of this?"

S/N "Well maybe you should have a word with the doctor and he can explain the ins and outs better."

All nurses reported that referring patients to the doctor was a most appropriate action for them to take although at the same time they well knew that the doctor was unlikely to reveal any more than did nurses themselves.

This knowledge produced another way of managing patients who were asking questions. By asking what the doctor said, then saying, 'If the doctor hasn't said so, well it can't be' or in the affirmative 'If they thought it was a disc and they haven't said different, then that must be right", nurses could then allow the patient to retain the idea that the lesions were not malignant and uphold the doctors affirmative judgement in such matters.

Although doctors asserted that it was up to them to decide about telling and nurses should refer all matters associated with diagnosis or prognosis, not all questions or statements were in such a direct form that the patient could be referred without the nurse exploring the issue further. For instance a nurse preparing a patient for theatre was faced with the comment,

"My mother died of cancer".

Another was met with

"Mrs. McL. was telling me her husband had a bad leg like mine. His was cancer. He had it amputated but he was dead in a matter of weeks."

Such statements obviously reflected something of the patients' feelings

about their illness, but they were not the kind of issue about which the nurse could simply tell the patient to ask the doctor.

Nurses were regularly asked questions about treatment - the significance of different types, reasons for change, why different machines were used and so on. Because communications were concerned with avoiding reference to the real nature of the illness, nurses responded to questions without exploration of any deeper meaning which may have lain behind them.

P. "Why did I have to come to this hospital after the operation?"

Sister: "Oh, just for a rest."

P. "Why am I having this treatment?"

S/N "To make you better of course."

These answers were, of course, not untruthful but they both minimised the information given about the patient's illness and maximised the idea of a good outcome.

Nurses were more often the focus of questions about number of treatments than were doctors. As a nursing officer said:

"It's the treatment they ask about when I'm on a ward round, not their illness. They are always on about the treatment. After all that's why they're here."

Focussing on treatment was relatively safe ground for nurses so long as discussion could be controlled. Patients compared notes and asked nurses about differences. Answers could have provided information about prognosis which nurses sought not to give, however it was possible to avoid doing so.

I10 "It's terribly difficult when you've somebody for a routine 20 and somebody only having 5. They compare notes and say 'I'm having 20, he's having 10' or 'I'm only getting 5, why is this?' Then of course you've got to say 'It's not the number, it's the rads that count. You see, if it's 10 they're cramming them in so you're really getting a double dose in each treatment. Instead of a month they'll only keep you a

fortnight. That's good isn't it'. You see you tag along with the patient, whatever he is thinking you make out it's better. You sort it out to make him feel it's less serious."

These measures were geared to be effective irrespective of the patient's state of awareness. If they did not know, their suspicions would not be aroused. If they knew their illness was cancer then they would suggest that their condition was less serious. However, because patients compared notes nurses could not say outright either that a radical course of treatment was a better omen or that a palliative course, requiring fewer fractions indicated a less serious condition. Rather they hinted that whatever treatment the patient was having was a better sign than any of the other regimes.

P. "I'm only having 5, why is this?"

S/N "Different conditions need different amounts. Your back only needs 5. Lucky you, you'll be home by the end of the week."

Communication was relatively unproblematic when nurses could call upon appropriate routines. However these were not always available, depending on the form of the patient's communication or the experience of the nurse.

When Routines were not Available

As pointed out above, patients made statements about others with cancer which had implications for themselves. They were not asking a question, but they were indicating an awareness and a desire to be open. Nurses had to find ways of diverting attention away from such difficult areas.

Patients not uncommonly projected a question on to other patients or sought the diagnosis of others in the ward. Nurses called their bluff.

P. "Some of the patients here are in a sorry state. Do they all have cancer?"

S/N "You should know better than to ask about other patients' diagnosis. But as a matter of fact no, we treat all sorts of things here. Radiotherapy is for other things besides cancer."

The fact that there were other conditions treated by radiotherapy and the occasional boarder and MRC patients meant that, while there was an overwhelming preponderance of cancer patients, their reply held a grain of truth. Their intention however was obvious in attempting to maintain the belief that it was not a cancer ward and that patients could be suffering from other conditions. Nurses had to learn such tactics and they were not readily available to less experienced nurses. At times this led to problems. For instance, the explanation that treatment was the cause of symptoms was over-generalised to patients who had not yet begun treatment. Sometimes nurses simply did not know how to respond.

While a young staff nurse and nursing auxiliary were bathing a patient she said:

"I'm having a lot of difficulty with breathing. All the systems are packing in now. My lungs are packing up and so are the water works. I'm done for."

The nurses pretended not to hear.

S/N "Now, would you like to put on a clean nightie? That would be nice and fresh."

On another occasion it was a student who reported that when changing a patient's urine drainage bag she met the question:

"Is this growth a type of cancer?"

She described her feelings:

"I was so upset, so overwhelmed I didn't know what to say. I felt all choked up. I couldn't answer no or yes or anything. I just got finished and took away the bag and I didn't speak. That was just about as much as admitting it."

Feigning they had not heard, concentrating excessively on the task at hand, excusing themselves to go and tell someone else, were all means of avoiding answering.

All grades of staff found themselves in difficulties when patients became emotionally upset. This was exacerbated when patients referred to their illness as the cause of their outburst. Nurses had to divert attention away from the illness and attempt to focus elsewhere.

Patient crying in a single room:

P. "I know it's cancer I've got. He (doctor) said it wasn't but I know that's why I'm here."

S/N "Now now Mrs. B. Settle down, don't cry like that."

P. "But I've got this."

S/N "Mrs. B., if you don't stop crying and worrying you'll start the bleeding again and that wouldn't do any good. Now settle down and I'll take you back to the other room. You don't want to upset the other patients do you?"

It was rarely that specific tactics had to be deployed for individual patients. Usually routine methods were available. However, on a few occasions ways of managing awareness had to be developed to suit particular patients. Changes in treatment plans could have provided clues to patients that there was a worsening prognosis. When treatment was stopped because it was not proving worthwhile then it fell to the nurses with the house officer to devise some plan to prevent the patient becoming aware. This could involve giving placebo drugs, explaining that the route of administration had changed from intravenous to oral cytotoxic drugs, or saying that treatment had halted temporarily until the patient regained strength to continue. Similarly patients transferred to a single room because of impending death, but who were aware of what was happening had to

have some explanation for the move. On one occasion an elaborate staging of a barrier nursing set-up was devised, involving the relatives as well as staff, with the patient being told she had an infection.

To summarise, communication was managed to prevent awareness and wherever possible routinised responses were used. Nurses varied in their ability to use such responses and all at times found themselves in situations in which no routine was readily available. On such occasions nurses had to make some response, even if it resulted in them avoiding the question completely, leaving the patient on some pretext, or turning the question into something which could be treated with humour.

Managing Patients who were Aware

While nurses avoided disclosure, they believed that patients who knew their diagnosis presented fewer interactional difficulties than those in a state of uncertainty and who may be seeking confirmation.

S/N "When you're working with patients, if they know and they've accepted it you can relax more. You're not always on your guard in case you let something slip. It's the ones that look at you and you know they're wondering. You have to be careful the whole time."

This kind of sentiment applied only to those patients who were regarded as having 'accepted' their illness. They had been informed or had somehow become aware of their diagnosis but did not raise the matter openly or seek prognostic information. They did not show strong emotion or become 'morbid' or make demands upon nurses for emotional support. Nurses described such patients:

S/N "Mrs. F. knows she's got cancer. She said as much, but she's determined to live from day to day and just take each day as it comes and be thankful. Now compare her with Miss N. She's just Miss Twenty Questions the whole time. She's up to ninety. Every time you go in there she's asking this and that. She's one who would have been better not knowing."

Still, although awareness may influence information seeking about diagnosis, this did not absolutely rule out information seeking about prognosis. Nor did awareness necessarily imply that patients would not seek to discuss the implications of their illness. However, given nurses' beliefs about the inadvisability of this kind of expression, they sought to minimise it. They did so by avoiding any reference to the illness, even when patients tried to show that they knew. One patient purposefully left an envelope addressed to a cancer charity on his locker but nurses studiously avoided any reference to it. Another patient exposed that he was reading an item on cancer in Readers Digest. The nurse's comment was that the magazine often contained interesting articles. Such expressions of awareness were relatively easy to ignore. On the other hand patients who knew and "had not accepted the fact", that is who more pointedly made it obvious that they wanted to talk about it, presented difficulties and nurses had to control open communication.

This was partly achieved by never raising the issue of their illness with patients known to be aware and avoiding lingering as far as possible with patients likely to raise the subject. Patients who persisted in introducing the topic of their illness in the presence of fellow patients had to be quietened. This nurses did by removing them to another room if they had created a disturbance among fellow patients and/or asking them or asking the house doctor to ask them to be considerate of other patients in the ward.

When patients raised the topic of cancer with nurses it was not

unusual for them to ignore the patient's statement and to introduce an entirely new element into the conversation with the rationale that this would detract from the patient's concerns.

N30 "She said 'I knew this was done for cancer'. Well I didn't know what to say and there was no point in dwelling on it so I asked about her home and her dog. I know she has a dog, and that would take her mind off it."

Displaying awareness of cancer sometimes accompanied information seeking about prognosis. Whatever the context, without absolutely denying cancer nurses tried to present an optimistic future. The following discussion occurred with a patient who had been told that she had had cancer but that it had been cured.

P. "It's cancer of the throat I've got."

N3 "What makes you think that?"

P. "Well all the cigarettes I smoke, I just have the feeling."

N3 "Why don't you give them up then?"

P. "If I've got it there isn't much use now."

N3 "That's not how to look at it. Be positive. Look at how much better you've been managing to eat. You're getting stronger day by day."

Another patient had a second primary cancer of throat for which a tracheotomy had been performed. Some time previously she had had a lobectomy for lung cancer.

I2 "I was just chatting to Mrs. J. and all of a sudden she came out with 'I know what I've got'. Then she went on to tell me she had one lung removed. She was worried about going up to the City and not having treatment because without the treatment and delaying it she wouldn't live. This is what's bothering her. Not the fact she has cancer but the fact that it would get bigger and kill her. But if she got the treatment it would be all right."

SB "What did you say to her?"

"I told her she would come back once the trache had settled a bit and we would begin the treatment then. It was better she was in the right condition then the treatment would be even more effective than if she was having problems with her breathing. I think she accepted that."

While it was not always easy to be positive about the patient's future, nurses utilised strategies to encourage the idea that the treatment would "do the trick" given time, that patients should plan a return to work or a holiday, and see their disability as transient. Nurses quoted other patients who had similar conditions as positive proof that the illness need not be fatal. The same patient, Mrs. J., asked another nurse about her prognosis:

S/N "Mrs. J. asked me if people with a trache lived for long. I always try to tell some of the truth, just bend it a bit one way or the other rather than tell an outright lie. I told her about a man who had a trache and how he used to come back to the ward to visit us. He's dead now but I didn't tell her that."

SB "How did she react?"

S/B "She asked me if he just had one lung but I told her I didn't know. I said my husband has just one leg and he manages to do everything everybody else does only a bit more slowly and I have two legs and I can't climb a flight of stairs without getting out of puff. So having one lung wasn't so bad."

Nurses usually tried to engender the idea of a certain future but there were occasions when patients knew that their prognosis was grave. Routine communication techniques which promised a rosy future were then considered inappropriate and betraying the trust patients had placed in nurses. However, rather than acknowledge the truth, nurses maintained the same position when they were in a situation of uncertainty about how much the patient did know.

Sister: "He worries me because he knows what's wrong with him."

S/N "Yes, it's the way he looks at you. It's as if I know and you know and you know I know."

Sister: "He asked me where I went for my holidays and when I told him he said 'I always wanted to go there'. I said 'Well, why not make arrangements for when you get out?'. He said 'Do you really think so? I'm not going to get out of here?' I could have bitten my tongue off. But I said 'You go ahead and make arrangements'. He knows all right."

S/N "Aye, I think he's twigged. It's the way he looks at you every time you go in."

Although nurses suspected that the patient may know the diagnosis still they need not have developed certainty about their prognosis and nurses were still at pains to avoid suggesting that the illness was advanced. Nurses would never purposefully reveal to patients that they had a poor prognosis. When patients were being transferred to homes for the terminally ill, the organisation and the name of the home were not mentioned. If patients asked if it was the designated place, then they would be told it was only a temporary measure. Constructing a hopeful future in the face of what appeared to them as blatant contradictory evidence was engaged in by nurses and doctors alike. Together they entered into collusion in an attempt to control awareness despite some nurses' stated reluctance to do so.

Disclosing

It was rarely that nurses would deliberately disclose information to patients which doctors had withheld. This was known to occur only three times during the course of the study and only observed to happen once although the actual words spoken were not heard. Only the most senior staff - ward sisters, and a senior staff nurse, were prepared to shoulder this responsibility. In each instance however it was the patient who initiated the situation which eventually led to the nurse acting in an exceptional way. A situation of privacy was contrived and it was the patients who asked.

Sister: "Miss V. asked to have a word with me. We were in the corridor so I asked her to come into the duty room. You remember she was having full treatment for abdomino-pelvic cancer."

SB "Yes, I know her. She has developed some other nodes now hasn't she?"

Sister: "She was looking worried. She asked me if the lump in her neck was the same as in her abdomen. I said yes, it was the same. Dr. G. wasn't very sure at first but he told us it's definite spread so when she asked I said it was. Now she said 'Thank goodness someone has told me at last, now I'll be able to prepare myself.'"

SB "Why did you tell this particular patient?"

Sister: "Well I think she had a pretty good idea anyway. She wanted to know. But I wonder if I did the right thing? I think I did because she thanked me for telling her. She said I had been the only person who had been honest with her. I felt then that this was worthwhile. This meant a lot to me for her to say that."

Sister: "Miss D. knew she had cancer, she had been told that right at the beginning when she had the mastectomy. But she wasn't really sure what the hypophysectomy was for, though she suspected. She asked me if it was to stop the spread and if her leg problems were a sign of this. I told her, agreed with what she said. I wouldn't usually do this but I thought she was open about her cancer and she was probably a person who would accept it. Usually though I would tell patients who came straight out with it to ask their consultant."

This incident happened when the patient had asked for help to bathe.

Nurses disclosed when the only feasible alternative would have been to tell a lie and when patients themselves had managed to convey that they had a good idea about their condition and would react in a reasonable manner. Not to have confirmed the patient's suspicions in these circumstances would have meant a loss of face for the nurses and this they were not prepared to risk.

Nurses were rarely a formal source of information to patients and only exceptionally did they break the rule that nurses do not tell. As we shall see later, they sometimes unwittingly and informally passed on information to patients but, because patients' state of awareness and the information given to patients featured little in their discussions, nurses usually remained unaware of these events. How nurses discussed patients is important however because

it was here as well as through observing experienced nurses, that students learned how to manage communication. The next and final chapter about nurses considers how they learned about communicating with cancer patients.

CHAPTER 11

HOW NURSES LEARNED ABOUT MANAGING COMMUNICATION

The study did not set out specifically to examine how nurses were taught how to cope with communication. However in the course of the study and with an increased interest in nurse education, it became apparent that the formal nursing curriculum, what nurses were taught in the classroom, was of little help to them in providing assistance to cope with either the emotional distress that working with cancer patients can bring or the specific interactional difficulties which are inevitably encountered.

Experienced nurses had learned how to manipulate the communication network. They had become familiar with the types of issues patients were likely to raise, the problems they presented and had well developed strategies to avoid becoming entangled with difficult interactions. Students or less experienced nurses on the other hand were in the process of learning not only the types of problem which working with cancer patients posed but also ways of handling such problems. While this study was not concerned with the management of communications about dying, it was apparent that an inextricable link existed between cancer and death among nurses. Many of the deaths they witnessed were not particularly easy ones.

Encountering patients in the wards who were dying as well as patients readmitted with metastatic cancer added to the feelings of the hopelessness of treatment. Coupled with this was the fact that once patients were discharged most of them were never heard of again except for news of their death.

Managing communication with patients also involved nurses in managing their own feelings about the seemingly inevitable outcome of the illness as well as the mutilation caused by surgery or

extending disease. Few opportunities presented themselves in wards for discussing how they felt about their work or the difficulties encountered with particular patients. Nurses tended not to share their difficulties with each other.

Nurses' communication with each other

The daily ward report sessions, attended by all grades of nurse and nursing auxiliaries, were considered by the ward sisters as a teaching opportunity as well as a forum for the exchange of observations about current patients and imparting information about new admissions. Less experienced nurses were able to learn how their seniors discussed patients and gained a flavour of what was important in patient care.

At interview nurses had stated the importance of nursing patients according to individual needs. The empirical evidence showed that individuality featured little in what was communicated to patients or how they were discussed at reports. Patients' state of awareness or what they had been told about their illness was not an integral part of what nurses were told or reported back about patients except in exceptional circumstances. Most often nurses did not know whether or what patients had been told or how they perceived their illness. When the nurse in charge passed on details of new patients, if the synopsis of case notes sent to the ward indicated any information of whether patients had been told then this was passed on along with details of the patients' pathology and proposed treatment at the first ward report after admission. Similarly if a patient transferred from another hospital arrived with a transfer document then, if there was anything to be reported about what the patient had been told, this was passed on. These written communications to

the ward were always in the briefest of terms 'Patient not told diagnosis', or 'patient informed of diagnosis' and applied to only a small minority of the patients. Nurses reported:

"Miss M., 64, recurrence of pelvic ca. Didn't know what they're going to do with her. She knows what's wrong and this is a recurrence of her tumour."

"John B., 42, ca. bladder. For EUA tomorrow. He knows his diagnosis."

Patients anticipated to cause problems would be commented upon at reports:

Sister: "Miss W., 58. She's had surgery twice for ca. rectum and now she is having 10 treatments with 5-fluouracil. She's going to be a right handful. No sooner was she in the door than she jumped on poor Dr. H. to ask if she would be cured. I can see we'll have problems."

Sister: "Mr. F., 63, previously treated. I'm not sure what his diagnosis is. He's not in for treatment. He knows the score and he was suicidal so we've got him. You'd better keep an eye on him."

When the senior nurse had gleaned information about whether patients had been informed by the consultant then this was passed on to colleagues. Again, however, this usually lacked precision.

Sister: "Mrs. F. Dr. B. had a word with her downstairs. He said he put her pretty well in the picture. Whatever that's supposed to mean."

S/N "Miss G. Dr. G. thinks there's some spread but he hasn't said anything to her yet about treating it."

Sister: "Dr. T. told Mrs. W. She didn't mention it this morning and she looks as if she's accepted it O.K."

While these instances were raised which informed nurses that patients had been told something formally, the patients' response to this information was not detailed. "Accepting it" meant that the patient had not introduced the topic and this was interpreted as being a good omen for the patient's eventual reaction to this knowledge. Occasionally however specific interactional difficulties which had

been encountered were given mention.

S/N "Mrs. J. Everytime you go in there she just looks at you as if to say we both know what's going on but neither of us will say. She gives me the creeps."

S/N "Every time I go into Miss T. she looks as if she's going to ask something but she never does. If you ask her if she's all right she just says she's fine."

Sister: "O.K. maybe I'll go and see her one day when Doctor isn't around. They're more likely to tell me things when I'm not on the ward round."

S/N "I think she's realised, you know. She's got that look about her and she's asking far more questions than the last time she was in."

Sister: "Well she's not daft. She's bound to know what's going on. She's been asking when Dr. S. is going to tell her what they found at the op. Just have to fob her off as best we can."

These brief allusions to patients' state of awareness or the kinds of difficulties presented did little to help students or new staff nurses know how to recognise patients who were expressing difficulties or how to handle them. Similarly they were not recorded in the nursing kardex so nurses who did not attend the ward report were unlikely to hear again unless patients continued to present difficulties.

Students said:

"We never get a complete explanation. Only that so and so is having such and such treatment. Or they've had this op. and whether they're for radical or that. Nothing about how the patient feels about it."

"Ward reports just give us the bare essentials, things relevant to the nursing care you're here to give. We have to find out through the grapevine if the patient knows what's wrong and that kind of thing."

But even if nurses had somehow managed to assess what patients knew, this would have had little effect on how they interacted since communications were slanted in the same way, irrespective of the patient's state of awareness.

In unusual circumstances, how a particular patient should be

managed cropped up. Tactics had to be considered for the control of information.

S/N3 "The neuro people said we were to stop all drugs except analgesics and just to give aspirin. Best not to tell what it is. What do you think? He's bound to know it's aspirin."

S/N5 "No, not necessarily. Why don't we just say it's a new thing."

S/N4 "If he asks we could tell him it's another drug the doctor's trying out. A new drug."

S/N3 "Well I only hope he believes it."

S/N2 "Mrs. A. has been asking why she was only having 5 treatments. We told her she was too weak to have more treatment so she would go home and come back when she had more strength."

S/N6 "I don't agree with that. That's wrong when it's obvious they're terminal."

S/N2 "Well it was Dr. K's idea, and if it makes them feel happier, what's the odds? It makes them calmer if you tell them they can have more later."

S/N3 "But I told her the treatment was finished. Not all the patients get 20, it depends on the dose and she seemed happy enough then."

S/N6 "Yes, I told her too. Different things need different amounts and she was a lucky one needed 5."

S/N2 "Well she was asking why the others got 20 and she hasn't so we said she could come in again when she was stronger and have the rest of it."

While these differences were aired there was no decision made about which line should be taken with the patient or others in the future. Had the house officer used the routine explanation of different conditions requiring different number of treatments there would have been no need to report the incident and that nurses made different responses would never have been aired.

Student nurses did not contribute to ward reports except when they were asked specifically to report on the state of a dressing or some other physical manifestation. However, such meetings served to establish among students ideas of what their seniors considered

as important in patient care. This was reinforced by the formal teaching which students obtained which was confined to teaching about specific kinds of illness and the medical treatment regimes undertaken.

Sister: "When we teach we tend to dwell on things like radiation hazards and the different kinds of treatment. I feel that the ward reports are a bit of a teaching session but we need do a lot more teaching of nurses. But how can you teach about communication? I don't know if I could. Every day things like death crop up and we talk about it but only on a superficial level. We don't really know how to talk about things like that."

Formal teaching and report sessions were limited in both how much nurses were taught about managing communication and as an outlet for nurses to express their own feelings and what they had observed of patients.

Learning through Experience and Observation

Nurses were more likely to learn ways of communicating from their own experiences as well as watching other nurses at work. The more senior staff were able to pick up information from doctors but students relied upon their seniors and stressed this as a means of learning how to react with patients.

2nd year student: "Well being with the staff nurses or sister just making the beds or bed bathing. You watch how they talk to the patients who are there. Especially at the beginning you feel tongue tied and it's worse on a ward like this where you aren't too sure about what the patients know. I was with Staff C. one day though when this patient said she thought her pains were due to cancer. Staff asked her what the doctor said and it turned out he told her it was pleurisy so Staff said it must be that."

3rd year student: "You just learn from copying the others, Staff and Sister. It's difficult when you're a yellow belt (first year student) but you listen to the seniors. Now it's not so bad as at the beginning, but maybe we've just learned how to back out of questions easier."

As students gained experience they were able to apply the same techniques that they observed other nurses using or heard discussed.

1st year "Mrs. S. was awfully upset because she was incontinent.
 student: I told her that would just be the treatment taking
 effect. At report though we were talking about it and
 it seems she's got a pretty big tumour."

SB "Why did you tell her it was the treatment?"

1st year "I don't know really, maybe it's because I've heard Staff
 student: saying that to other people."

Nurses were not often open about their techniques for handling
 particular problems. They did not have to account for their
 communication. Routine responses were usually available but some
 nurses had developed their own ways of handling an awkward situation
 which would not clash with others. Occasionally a student would
 come to discuss a patient with the investigator and this provided
 an opportunity for one Staff Nurse to relate her particular method.

Senior "Mrs. L. would be a good candidate for you."
 student:

SB "What's she been up to now?"

Student: "Well I was helping make her comfortable and she said she
 thought the treatment wasn't going to work. She was
 getting weaker and she thought her number was up."

SB "Did she say that?"

Student: "Yes. She really said she was dying, didn't she?"

SB "Well it could be true what she was saying. How did you
 react?"

Student: "I didn't know what to say. I never do. I felt upset.
 It's as if I know and won't tell her and she knows."

S/N "When this happens to me I always say there's only one
 can answer that, and that's the man up above. I don't
 know if they'll think I'm religious or what but that's
 what I always say."

SB "What kind of things do the patients say to that?"

S/N "Usually they change the subject."

Student: "Yes, that's a good thing to say. Gets you off the hook."

The Staff Nurse said when the student had left:

S/N "It gets you out of an awkward spot. Probably some people think I'm stupid saying that."

SB "Why do you think folks would think you stupid?"

S/N "I don't know. I'm sensitive to patients and sometimes I feel I have funny ideas."

SB "Do the others think you have funny ideas?"

S/N "Well it's not something we discuss really. Sometimes it comes up but we're usually too busy, we never have enough time for this kind of thing."

It was apparent that some nurses were aware of particular patient needs and were sensitive to patients' expressions. One staff nurse for instance knew that a patient was frightened, the patient literally holding on to the nurse but the nurse did not know how to deal with this apart from getting away from the patient, or how to tell her colleagues about her difficulties. It was as if nurses should not experience such feelings. If they did there was no way of obtaining assistance to cope with them.

Early experiences with patients remained salient, especially when nurses felt that they had led to harmful effects on patients. It was not difficult to attribute subsequent events to their actions but there were no opportunities to raise this kind of matter with senior nurses.

I12 "It was a man. He kept asking how he was doing and what was wrong with him. Quite honestly at first we didn't know and said the usual kind of thing. You know, he would be back to himself in a few days. But then he got annoyed, the doctors seemed to pass him by. We told the sister what he said and got the doctor to have a word with him. They told him he had cancer and from that day on he was a changed man. He got ratty with us and sort of gave up. I've thought a lot about that since."

SB "What makes you think about it now?"

I12 "Well if it was right to tell him. It's up to the doctors, they know more than we do. But if we hadn't told, he might still have been alive. So it makes you wonder if the doctors were right all along in not telling him."

From such events which nurses interpreted as going wrong, they experienced guilt reactions. Similarly if a young nurse exposed how she felt to a patient, thus unwittingly conveying information, she considered this inappropriate. To show emotion with patients was unprofessional on two counts. It conveyed that the nurse was becoming involved with the patient which they had been told to avoid; but it also risked exposing information to the patient which nurses believe they were not entitled to give. At the same time they thought it risked harming patients by conveying information which was not in their best interest.

Nurses who had not yet decided what was really appropriate behaviour were placed on the spot. However, because they did not share their experiences with senior colleagues they were left to wonder and to struggle with their feelings.

Student: "You get the patient who asks 'Will I be cured' or 'what is this lump'. Well I feel inadequate to deal with it. Partly because I don't know enough. But I always feel I'm beating about the bush because I can't give them an answer. I don't know what I'm expected to say. Sometimes I don't say anything but that's just as bad as telling them something that's not true."

The spontaneity with which inexperienced nurses approached the patients at times led them into trouble. They had to learn not to ask patients about their illness and to control their expressions of sympathy. Attempts to be encouraging sometimes misfired. The following incident occurred during the exploratory work and was recounted by the student. Other nurses had also learned about it. This was one of the rare occasions when a doctor was summonsed to see a patient because of an outburst directly associated with developing an awareness of metastatic spread.

- I5 "On Thursday Mrs. W. said she knew what was wrong with her and all this wasn't worthwhile. She was going to die, she was going to die. She said her sons had been angry with her about it and told her she was being selfish and I quite agreed with them. After all I said 'You've had your operation and you're feeling better. You've a lot to look forward to. All this treatment will have given you years'. Well she took it the wrong way. She took it I only meant a couple of years and I didn't realise until later I had said anything wrong."
- SB "What made you think you said something wrong?"
- I5 "Well I put my foot in it. She got so upset we had to get Dr. R. to see her."
- SB "Why do you think you put your foot in it?"
- I5 "Well obviously Sister thinks I put my foot in it when I spoke to her on Friday, she said, 'Well you will have learned through this'. But I said to Sister, I said I still feel I haven't said anything wrong. She said, 'You have to be careful. Some of these patients are as sharp as needles'. And I agree with this, but Mrs. W. has just been making a lot of fuss. I was awfully upset about it."
- SB "Well that's understandable."
- I5 "It was the thought I had harmed somebody. I would hate to do this. I'm awfully chicken about things like that. I had a cry over it. Oh I don't know if Sister thinks I put my foot in it or not."
- SB "What do you think now then?"
- I5 "I don't think I said anything wrong. But it's warned me. It's been a warning to be more careful with patients, but I'm sort of happy go lucky and that's where I made my mistake. I was too relaxed. I'll need to learn to be on my guard more."

It was fear of such experiences which led senior nurses to avoid alluding wherever possible to the patients' illness, something students came to learn as the least troublesome way to proceed.

S/N "I never talk about the illness. I leave it up to them and just tag along with the patient."

S/N "If the patient brings it up that's all right, but I wouldn't. You don't know what they know or what they're thinking so it's best avoided."

By avoiding talk about cancer and its implications for patients once they left hospital, nurses were unable to develop any sense of whether or how they could have helped patients with actual or

potential personal and social problems associated with their illness. This was in keeping with the whole rationale of the department. As well as a belief in the benefits of avoiding disclosure, there was no perceived need to develop abilities to assist patients who knew that they had cancer to express their feelings about it if they so wished. This meant that it was not possible to develop abilities to identify when patients may have benefitted from such help.

Similarly, although nurses did not generally formally impart information about diagnosis or prognosis, there was no way of ascertaining the benefits to patients of the strategies they employed to avoid disclosure. Because nurses were not held accountable for such matters, there was no pooling of information and hence no way out of the cycle.

In any case nurses believed that communicating and interacting with patients was something which could not be taught. How to communicate was considered to be acquired by the accumulation of experiences with patients and by learning from how others did it. Since it had to be tailored to the individual it was not like learning a procedure.

- I11 "Well each patient is different, they are all individuals to be treated as he or she comes. You can't really teach that."
- I8 "It's something that develops during training through a general interest in people. It's not something you could be taught in lectures."

For practices to develop in line with the nurses' stated desire to provide care according to individual needs, then extensive changes in accountability for and assessment of outcomes of communication practices with patients would have to be developed. Nurses however, rarely reported their communications either verbally or in writing.

They had neither the time nor inclination to do so. There was no means of structuring information gained about patients or assessing the outcomes of particular interventions. Developing principles or inductive theory on which to base practice therefore was not possible. The 'common sense' methods used by nurses to communicate, the tactics and routines learned through experience, effectively cut off alternative learning strategies. This precluded information becoming available which would confirm or disconfirm assumptions held about patients and the value of current practice for either nurses or patients.

CHAPTER 12PATIENTS' STATES OF AWARENESS

The preceding chapters considered the basis of doctors' and nurses' communication practices with patients. Attention is now focussed on the patients themselves.

The patients in the study formed a heterogeneous group not only in terms of the type of malignancy, the stage of the disease, its duration and prognosis, but also in regard to adjustment to cancer. They shared a common identity only in so far as they all had cancer and, with the exception of a few terminally ill patients, were undergoing some form of active treatment. In other words, something was being done about the illness. Adjustment to cancer is not a global reaction to a single event. It is the sum of many piecemeal reactions to ongoing events and the many stresses encountered in the variable course that the illness may take. While it has been suggested that communication behaviour is integral to coping strategies,^(1,2) investigating the composite nature of coping was beyond the competence of the author and the scope of the study. Adjustment to cancer is limited to an examination of communication processes and their relationship to awareness. This is not to deny the importance of other intrapsychic and environmental factors in coping.

The analysis is based on two types of data. First conversations held with patients over the period of their stay in hospital. Some patients were encountered soon after admission and data collected periodically thereafter. For others, some relevant remarks or questions observed at a ward round or review clinic prompted follow up, and asking patients about their knowledge of their condition and

desire for information. Patients had already been informed about the study and so asking questions about communication did not appear out of place. Most patients were very willing to talk about their experiences. Such conversations were held with patients throughout fieldwork except for the periods when attention was focussed on the systematic recording of nurse patient interactions.

A second source of data were the interactions engaged in between patients, fellow patients and hospital staff in all of the settings in which they encountered each other. When staff were involved, the observer played largely a non-participant role, taking note of relevant events but a more active role was engaged in within patient groups. While this type of data was collected throughout the study about hundreds of patients, a small number of patients were observed closely throughout the duration of their stay, providing very full data about communication patterns and about how they operationalised their particular information needs in relation to adaptive mechanisms. This was important in considering the processual nature of patients' adaptation in relation to communication with significant others. Not all patients passing through the wards could be assessed and it is a methodological weakness that some defined sampling method was not employed to provide a quantitative analysis. From the data obtained it was possible to identify prominent awareness states and associated patterns of communication.

Patients' state of awareness could only be assessed by how much they were prepared to articulate either to me, to members of staff or to other patients. That patients did not articulate that they knew they had cancer or knew their prognosis does not mean necessarily that they did not know or did not suspect. They may well have done, but were unable or unwilling to share it at this time. Behaviour

with staff and other patients was interpreted in the light of desire for particular kinds of information in order to develop or maintain a particular interpretation of the illness. This could take the form of avoiding information or selective information seeking in order to minimise the threat which could stem from acquisition of the facts. Alternatively patients may seek the facts as their current preferred way of coping. The process of changing interpretations of their situation was associated with dynamic changes in information behaviour.

This chapter attempts to explain the variety of states of awareness encountered and discusses how awareness and associated communication may change over time.

States of Awareness

While awareness is in no sense a static category, at any one point in time it is possible to say with reasonable certainty what patients know about their illness. This rests on the assumption that what patients say reflects their awareness of their condition. Accordingly, patients who said that they knew they had cancer were categorised as knowing while those who indicated that they could have cancer were included as suspicious.

"It's a tumour but that's not to say it's necessarily malignant."

"I think it's a touch of cancer myself but nobody's said so I'm not really sure."

Patients who have no indication that they knew or suspected the nature of their illness were categorised as not knowing together with those who denied that it was cancer.

"It's not cancer. They don't know what it is. They don't seem to be able to make up their minds what's causing the swelling."

Awareness is also relevant to prognosis. Prognosis however is a complex phenomenon. The outlook for the illness depends on a number of factors and is variable over time. Ascertaining awareness is therefore a more difficult matter and is more than knowing whether the illness will prove fatal. Prognosis is more a matter of knowing the extent and likely course of the illness rather than a time scale. Accordingly patients varied from knowing that the illness would prove fatal through knowing that it had spread but may still be contained to ignorance of the likely outcome.

McIntosh⁽³⁾ categorised patients on admission to a malignant diseases unit according to whether they suspected, knew or did not suspect that they had cancer and whether they wanted information about diagnosis and prognosis. He found that the large majority of patients already knew or suspected cancer. A similar impression was gained about patients in the present study.

Only a minority appeared not to be at least suspicious of their diagnosis. Some at one time had suspected cancer but had been led into believing that their illness was something else while others apparently did not suspect.

That most patients knew or were suspicious is not equivalent to having been formally informed about their condition, as happens to most patients in the United States.⁽⁴⁾ Experiences associated with the illness had to be given some interpretation, they did not exist in a vacuum. How patients interpreted their experiences and their degree of awareness was more a product of their own lay knowledge of the peculiar characteristics of cancer and its treatment, than of formally imparted information.

Awareness Prior to Admission

Some patients had suspected cancer even before seeking medical advice. For some this prompted action while for others fears resulted in delays. Cancer was associated with localised palpable or visible lesions - breast cancer and rodent ulcers being the most obvious examples. With internal lesions giving rise to vague, systemic symptoms patients were less likely to make an immediate association between their symptoms and cancer.

"I just put it down to my age."

"I was a bit off colour, got tired more than usual and sometimes I felt full up, bloated inside."

When other family members had had cancer, this precipitated awareness.

"When I saw the lump I suspected right away. My mother had the same thing and you know some illnesses run in families."

The promptness of referral to hospital and subsequent treatment was an indication to some that it was serious. Also, knowing others who had gone through the process of diagnosis provided information about the meaning of various tests and examinations.

"I had a bronchoscopy at the City. One of my mates had that for cancer so I knew right away it was cancer they were on to."

The nature of surgery was also a confirmation for some that their suspicions had turned out to be true.

"When I got back from theatre the first thing I remember was feeling to see if they had removed it. Then I knew straight away."

While symptoms, tests and surgery need not convey cancer, referral for treatment to the Department provided a clue which could not be denied.

"Where I come from everybody knows it's the cancer place."

"You don't get radiotherapy for warts and that kind of thing."

One patient who had been referred to the consultant was to be seen at one of the peripheral out-patient clinics. She had never heard

of him before and asked a nurse in attendance who he was.

"She told me he was a cancer specialist. What a shock it was. Before that I thought it was just woman's trouble."

All of the patients could have been informed elsewhere at the time of diagnosis or surgery or by their General Practitioner. In practice, this happened rarely. Some patients were told there was a neoplasm, a tumour, active cells, some consolidation in the lung, a blockage which had to be removed. The fact that it was cancer was not volunteered but the question had been posed.

"He said they had removed the offending tissue and I would have treatment here. I knew at once it must be cancer so I said was it malignant. He said it was a small tumour. It was malignant all right."

"I was told before the operation that if there was anything suspicious they would take it away there and then. So I said was it cancer then. He said it had been, but just an early one. They had caught it before it had a chance to do any real damage."

General Practitioners also played the role of not volunteering a diagnosis, but this did not deter some patients from asking and having their suspicions confirmed.

P. "I had a good idea it was cancer. I asked my own doctor, in fact."

S.B. "What did he tell you?"

P. "He hummed and ha-ed and said it could turn nasty if it wasn't seen to now. Well either it's cancer or it's not. So from what they've said the tests must have shown it up."

Of course patients' interpretations of available information varied.

Some attributed a specific cause to their illness:

"It was my grandson. He knocked my pipe into my gum. A sore developed and it's just got bigger. I had to go and see about it."

"I dieted too quickly, that was the start of all this. Now see where it's got me."

Such causative explanations were at times maintained and helped patients persist in the belief that they did not have cancer.

P. "It was after I had pneumonia. I was in the Cameron with that in March and it wouldn't clear up. I had another X-ray and there was still some consolidation there. This treatment should clear it up now though."

S.B. "What's causing the consolidation?"

P. "It's what's left of the pneumonia. It must have been a real deep seated one."

While all patients had had opportunities to learn about their illness prior to admission and most were at least suspicious, a few patients were encountered who did not suspect cancer.

Patients who did not suspect cancer

A few patients had fixed alternative diagnoses in their minds and made no moves to alter the nature of that diagnosis. Such explanations of their illness had been given or else deduced from the nature of their symptoms. For example, an adolescent with a fibrosarcoma of femur was convinced his was only a temporary illness and would certainly be cured. The best outcome for this boy after treatment would have been a hind quarter amputation of his leg. He had no idea of the nature of his illness or its possible future treatment.

P. "It's a softening of the bone in my leg. I got a knock playing rugby and then it got sore and I had a limp. This treatment will get it better again."

S.B. "What caused the softening, do you know?"

P. "No, I don't know. All I want is to get back to playing rugby again. It's taking a lot longer than I thought. Even if you break your leg it doesn't take all this time."

S.B. "Why do you think it's taking such a long time?"

P. "It's what's inside the bone. Must be some infection or something like that."

All of the staff helped sustain this belief by talking to the lad about playing rugby again which was his current passion. They gave no hint of the seriousness of the condition. He did not ask questions

about his illness except to ask why he had to have X-rays taken regularly. The explanation, to 'keep an eye on how it's progressing' satisfied him that he was getting well again. He saw no reason for pessimism.

Patients who had suspected cancer but believed otherwise

Some patients had feared that they had cancer but had been persuaded otherwise and so had no reason to establish the real nature of their disease. One such patient was aged thirty-four and had a seminoma of testes. He knew that he had had a tumour removed but had come to believe that it was benign prior to admission.

P. "I went in to have it investigated. After the operation Mr. S. took me aside into the dressing room and explained that it was a tumour and they had had to remove it in case it got bigger."

S.B. "What did he say exactly, can you remember?"

P. "He said it was a tumour on the testicle and the whole thing was better removed. Just to be sure I would have treatment here as well."

S.B. "Did he say what kind of a tumour it was?"

P. "No, he didn't. I wondered about that and I looked it up in the dictionary when I got home. I thought the worst of course. I know they treat cancer here, but there are two types of tumour, benign and malignant. Now if it had been malignant he would have told me. I'm not the morbid sort. It must have been benign. This treatment is just belts and braces."

This patient was closely observed during his stay in the ward. He did not ask any questions at all about his diagnosis or the outcome of his illness. The registrar dealing with the patient volunteered explanations of the various tests and examinations, none of which aroused any suspicions of malignancy for the patient who was well satisfied with the information he received. Toward the end of his treatment he was given very reassuring information about his prognosis.

Dr. T. "I might be sticking my neck out but you can anticipate no further trouble from this."

Prior to discharge he still maintained the belief that he had a benign tumour. With the reassuring news about prognosis, this served to reinforce his belief.

P. "I'll be back at work within a couple of weeks. This treatment takes more out of you though than you think."

S.B. "Why did you have to have this treatment after your operation?"

P. "It was just a case of being perfectly sure. There was a tumour but it was pretty harmless. They did this treatment for my benefit really. I suppose they were afraid of anything developing. But after what Dr. T. told me I know there isn't anything to worry about. You don't get guarantees like that very often."

S.B. "Are you satisfied with your treatment here, about how you've been kept informed?"

P. "Yes, couldn't have been better. I suppose it's because Dr. T. is young. He treats you fair. I certainly couldn't complain."

Patients like this maintained their belief during their stay in hospital. They did not try to establish the nature of their condition any further, and the reassurances offered inhibited any desire to seek further information about the outlook. Such patients were entirely satisfied with the information they had been given.

Patients who did not at least have suspicions about their illness were in the minority. The vast majority of patients could not completely disregard the evidence that their illness could be cancer. They engaged in attempts to minimise the information which would suggest cancer while seeking information which would help sustain a belief that the illness might not be cancer.

Patient who originally suspected cancer but changed her mind in hospital

Mrs. Y. was a middle aged woman who thought she had cancer on admission to the ward. Within a few hours however she was beginning to change her interpretation after a discussion with her consultant

with whom she had not spoken prior to admission.

Mrs. Y. "When I was told I was to come here I got really worried. Though nobody said anything, I thought it was cancer. I was up to 99. But Dr. S. told me it was an ulcer at the neck of the womb."

S.B. "Can you remember how it was explained exactly?"

Mrs. Y. "When I went down to the clinic I was shaking like a leaf. He explained about coming for the treatment for the ulcer. I said 'Is that what it is, an ulcer?' Now he was surprised I hadn't been told before that was what it was. It could have saved me an awful lot of worry. I was tormented by it."

S.B. "Were you relieved at that explanation then?"

Mrs. Y. "Not half. That explained a lot. I'd had pain when I passed water. It must have been a raw bit and that would cause the discharge as well. They tell you everything nowadays. There was a time you were scared to ask doctors and matrons. Now they are more forthcoming."

The explanation that it was an ulcer allowed the patient to interpret her other symptoms within this framework, reinforcing the belief that it was something other than cancer. Relieved at this diagnosis she maintained it during her stay, elaborating her knowledge that it could turn to cancer but believing that to be told it was an ulcer meant that it had not gone that far.

Mrs. Y. "I've had two insertions (of caesium) and I'm almost finished the treatments now."

S.B. "You've had a lot haven't you?"

Mrs. Y. "Yes but it's better. Dr. S. said it was better if you had the whole course. You see you could get infections having the ulcer and that could turn into cancer eventually. Mrs. S. told me she had cancer but mine hasn't got to that stage. It's just an ulcer."

S.B. "Are you worried about it?"

Mrs. Y. "Not really now. I was when I thought it was cancer. I was scared stiff. But Dr. S. told me it was only an ulcer and with all this treatment.... But it's worth it in the long run. Mind you I didn't think that a while ago."

S.B. "Why not?"

Mrs. Y. "Well I thought if it's cancer there's no point in any treatment. It was such a relief to know it wasn't that."

And so even strong initial beliefs that the illness was cancer could be modified despite there being plenty of evidence to the contrary. She even struck up a friendship with a patient who admitted that she had cancer but managed to perceive differences between their symptoms which reinforced that her illness was different. She had still the idea that it could turn to cancer - but there was a great difference between that and having established cancer. Any challenge to this construction was overcome by interpreting symptoms in line with the diagnosis of 'a raw bit'. She also overcame the belief that if it was cancer then there was no point in any treatment because here she was having the full works. Under such circumstances any chance that the ulcer could turn to cancer was minimised.

The great majority of patients were more suspicious than this or else knew that their illness was cancer. Only a minority deliberately chose to alter this conception by confirming their diagnosis or extending their knowledge about prognosis. They preferred to remain uncertain. Some stated this quite clearly. They wanted to remain in ignorance of the facts. That they made this so plain indicated their suspicion that something was seriously wrong.

P. "They said the swelling was due to a hiatus hernia. That's what's making swallowing difficult. That's what they tell me, but I've stopped asking questions."

S.B. "Why did you get transferred over here then?"

P. "I told you, I don't ask them any questions."

P. "A bone in my back has collapsed."

S.B. "How did that happen?"

P. "I don't know. I might have banged it on a key or something. I just shrugged it off. And they don't say anything about it. You just lie here wondering what it is."

S.B. "Haven't you asked about it?"

P. "I've been down twice but they don't tell you much. Only about the treatment."

S.B. "Have you actually asked?"

P. "Well I don't like. Maybe I don't really want to know. After all what you don't know can't harm you."

Rather than risk being told, and despite saying that they wondered about the cause of the trouble, these patients preferred to remain in a state of uncertainty. In this way they avoided confirmation of their suspicions. And suspicious they must have been, otherwise why not ask? Such patients claimed to need no further information. It was not that they were ignorant of their illness but that this was as far as they were able to go at this time. Unavailability of privacy, lack of time with doctors, a belief that the doctor would not tell the truth, even if asked, were given as reasons for not asking. A more potent explanation however, is that if they did ask then they feared they would have been told, and they were not prepared to face this prospect. Other patients could have cancer but not them.

P. "I told my husband not to tell me if they found something serious. My worst fear is if I have cancer. I would do something terrible. I wouldn't want to die of it. I would rather do something terrible to myself when I went home."

S.B. "What's the matter with your chest then?"

P. "I was told it was an inflammation."

S.B. "Have you asked for the details?"

P. "No. I didn't want to hear any more. The treatment will clear it up and then I know they keep a watch on me. Now if anything develops out of this it won't get very far. It would only be the time between check ups."

S.B. "How do you feel about it now?"

P. "When I got here I was just a bag of nerves. Dr. M. noticed how worried I was. He told me everything would be better after the treatment. That calmed me down. Half my trouble when I came was I was scared I would see horrible things. I was frightened I would catch something from the other patients. That's why I won't help with the washing up."

Such patients wanted to know that they did not have cancer and that prognosis was good. They were concerned with actively avoiding realisation by maintaining uncertainty. It was this uncertainty

which gave them hope - hope that the illness was not cancer - and if it was cancer, hope that it would be amenable to cure.

Patients' curiosity to seek information about their illness with the vulnerability such information could create was dependant upon the patients' level of fear. That is the extent to which patients sought information to confirm their diagnosis or extend their knowledge of prognosis was associated with how they conceptualised cancer in general and their own illness in particular.

Patients could not ask when they associated cancer with their own death. Take Mr. N.

Suspected cancer but did not ask

He was a married man with two children. His presenting symptoms were abdominal pain of which he had complained for several months. This became acute and he was originally diagnosed as an appendicitis and, some six months prior to this admission, had an appendicectomy. His abdominal pain continued however and 'my boss and my doctor put it down to malingering. They thought it was all in my mind'. The pain continued and two months later he was admitted as an emergency. At laparotomy a mass was discovered and a right hemicolectomy performed. He was diagnosed as having lymphosarcoma and two weeks later admitted for radiotherapy.

When asked about his illness he replied:

T.N. "It's some blockage in the bowel."

S.B. "What caused that?"

T.N. "It was left after they took out my appendix. It got kinked up, twisted like. That's why I had so much pain."

S.B. "What are you here for now?"

T.N. "I've to have some tests done and get the deep X-rays."

S.B. "Were you told why you were having this done?"

T.N. "Not exactly. I was told that there was some inflammation and that would be best seen to."

S.B. "What's causing that?"

T.N. "I think it was the length of time I had the trouble. This pain has been going on for months."

S.B. "Were you told anything else about it?"

T.N. "They weren't sure if it could be something in my blood. I had a sternal marrow done."

S.B. "What did that show?"

T.N. "I presume it was all right, they didn't ever say though."

S.B. "So it's some kind of inflammation?"

T.N. "That's what they called it. It could be malignant though."

S.B. "What makes you think that?"

T.N. "I just think it could be."

S.B. "Have you asked?"

T.N. "No, but I will before I'm finished."

And so, despite explanations to the contrary, Mr. N. suspected cancer and indicated that he would confirm his suspicions by asking while he was in hospital. During his treatment he showed fluctuations in mood - he became depressed and withdrawn when there was delay in beginning treatment. Some tests had first to be performed. Then he wondered if they had found evidence of a further malignancy. Once his treatment began he was considerably relieved:

"They must have been clear after all."

His fears were aroused again however when regular blood specimens were requested. He also overheard his consultant refer to 'lymph nodes'.

"I thought it was just my tummy, maybe there's something in my blood now. And these lymph nodes. I'm not sure what that means."

He did not voice his fears to staff however but expressed them to his fellow patients and to myself. When he went for his weekly visit to the consultant he sought reassurance that he was doing well and

was given it.

T.N. "Are my blood tests looking all right?"

Dr. S. "Oh yes. We just keep an eye on the white count. It's bearing up all right."

T.N. "That's a relief."

At the next clinic he said:

T.N. "You're feeling quite happy about me then?"

Dr. S. "You're doing very well. Time is going on now, almost half way. Your blood count is fine too."

He had also learned from another patients that if 'nodes' were present 'they show up on the surface'. That he had no lumps or bumps reassured him, at least it had not gone that far.

An error at the laboratory however indicated that the next white blood count had reduced by half. He was told by the house officer who came to take another blood sample.

Dr.C "You'll not be getting treatment today, blood count's way down." Therefore, despite reassurances from the doctors the current evidence was not in the least reassuring. He did not understand the significance of the blood counts. Also one of his room mates had had blood counts which were consistently high.

S.B. "You must be pretty fed up about it when you were doing so well."

T.N. "This isn't my year, is it? I've started to eat like a horse again. I always do that when I'm worried."

S.B. "What's worrying you?"

T.N. "Well, I just feel I don't know what's going on and what's behind it all. Brian's had the same (treatment) as me and he's all right. What's up with me?"

S.B. "Did Dr. C. not explain it to you?"

T.N. "Just that the count was down. He put it down to the treatment."

S.B. "So?"

T.N. "Well is it or isn't it? I suppose I'm just worried by the whole thing. I mean, if it's cancer, does this mean it's worse?"

S.B. "What makes you think it's cancer?"

T.N. "It's pretty obvious isn't it? All this. I'm going to ask when I get hold of someone."

He never did get hold of someone however. At his final visit to the consultant he was reassured that all was well.

Dr.S "Your last one tomorrow, Mr. N."

T.N. "That's a relief. I was worried when I thought you were going to stop it."

Dr.S "Well these things sometimes happen. You've done very well. I'll just have a last look at your tummy before you go, if you'll pop up on the couch.....that (scar) looks very nice. Feels fine. I don't think you'll have any trouble now."

He remained in a state of uncertainty about his diagnosis as well as his prognosis. While he said he wanted to know, he could not bring himself to ask.

S.B. "Did you ever ask Dr. S. about your diagnosis?"

T.N. "No, I didn't have a chance really. Anyway what's the point. I'm worried enough as it is without any more. I'll just have to hope that's the end of it now."

S.B. "What are you worried about now?"

T.N. "If it's cured."

S.B. "Why shouldn't it be?"

T.N. "I just feel I've had rotten luck. It would just be like the thing if it wasn't. I would like to know but I'm scared what they might tell me. I'm better not knowing! After all you never know what they might tell you."

S.B. "Why do you think it's better not knowing?"

T.N. "Well then I can at least hope for the best. They didn't stop the treatment and what Dr. S. said about this being the end of it. I'll just hope my luck's turned now."

S.B. "You've been worried a lot while you've been in here. How do you feel now?"

T.N. "I think I'm just a worrier by nature. (Laughs) So the wife says. I'm not happy unless there's something going on. Of course I'm worried but I've had good hopes. There's no point in getting into a state over it, that wouldn't do any good. I'll just try to put it all behind me now but with an illness like this you never know. It could be curtains."

Like other patients, Mr. N. would have liked to have been told that it was not cancer and that there was a good prognosis. However he was afraid that what he may have been told would have been even worse than he dared hope. There was no reason for him to know that had he asked a direct question he would not have been told. As it was the questions he did ask and the responses he obtained served to encourage him but were not sufficient to dispel his uncertainty. However, his fears of the information he could have been given discouraged him from asking. As his suspicion of cancer grew so he was also less prepared to seek a prognosis. He remained worried and uncertain. He was readmitted with metastatic spread while the study was still in progress.

Avoiding Prognosis

It is evident that a strong link exists between diagnosis and prognosis where information is concerned. As long as the belief can be maintained that the illness is not cancer the prognosis is unproblematic. Once suspicions are aroused however, patients' definitions of cancer bring into focus the question of prognosis. Knowledge of a poor prognosis would have destroyed hope just as maintaining uncertainty over diagnosis endangered optimism. For this reason many patients had no desire to acquaint themselves with details of their prognosis.

As one patient said:

"It's the uncertainty here that's hard to put up with. We're mostly in the same boat. You're not sure if at the end of this it's going to work. You could ask but that's not to say they would tell you. Anyway do we really want to know? I can hope now."

Patients who knew that they had had cancer treated previously placed some other interpretation on new symptoms.

"It was a spot of pleurisy. I think I must have been a bit run down. I expect I will be all right again before long. I'm hoping this will be the end of it."

Although some patients were aware that they could have a secondary, they were not prepared to discuss it openly with their doctor.

Mrs.J. "He said it was a softening of the bone; I think myself it's due to cancer. I had it treated before."

S.B. "Have you asked if that's what it is?"

Mrs.J. "No. I've not asked. I just hope they caught it early enough. There's not that long between check ups so it can't have gone very far. At least that's what I'm telling myself."

S.B. "Why do you think you've not asked?"

Mrs.J. "I suppose I'm just hoping it will be cured. If you ask - I don't think they can be sure anyway. They couldn't give you a guarantee with a thing like cancer so I'm better just to hope it's been seen to in time."

Patients who did not ask about prognosis, while wishing to maintain as hopeful a picture as they could also believed that 'doctors can't really tell anyway' or 'they won't say too much in case it worries you'. There was also a feeling that it was not fair on doctors to ask this kind of question.

"After all they've enough to do without us pestering them all the time with questions."

"They don't tell you that much but they know best. So if they don't think you should know something it's not right to ask them."

As it happened, even if patients had asked, staff were unlikely to give anything beyond vague statements implying an optimistic future. Patients could therefore avoid learning anything about prognosis from formal information sources by simply not asking. They were able to avoid and nullify the perpetual threat also by playing down the potential seriousness of their illness

"If it was bad I would be wasted and grey or yellow. I'm all right apart from this leg."

and explaining away the clinical facts

"I didn't need an operation. Just the tests. So that's in my favour."

The policy of not giving a diagnosis or prognosis thus allowed patients to maintain as hopeful a construction of their illness as the appraisal of other cues permitted. Avoidance of such a threatening reality was not a permanent state. The margin between states of awareness and states of uncertainty tended to fluctuate in response to what patients knew, how they interpreted events and the potency of the various cues available to them.

Instances of blatant denial were certainly present but even these had to be actively maintained over time. Inevitably some patients came to acknowledge that they had cancer as well as the severity of their condition. The next section deals with patients who sought information about diagnosis and prognosis.

Seeking to establish diagnosis

Some patients adjusted to their illness by seeking to find out more about it in an attempt to eradicate uncertainties about diagnosis and prognosis. These patients evidently preferred to face the unpleasant information they would be given rather than tolerate uncertainty. Some patients believed that facing up to problems was an appropriate way of coping with difficulties. Nevertheless patients who asked demonstrated that, by so doing, they would not give up hope. For instance

"I think it's better to know the truth. I can't be done with all this hocus-pocus. If I've got it then I just have to make the best of it. I'm not ready for a box yet."

Patients who sought a diagnosis were not unaware of its significance but they did not see cancer as leading inevitably to death. When discussing their diagnosis, not infrequently they referred to people they had known who had had cancer and were still alive or whose

death they attributed to some other cause.

"Just because you have cancer doesn't mean that's the end of it all. My aunt had cancer for thirteen years and she died of a brain storm. I think you can worry yourself to death."

Equally they knew people who had died, but saw their own cancer as not necessarily fatal:

"I just have to hope now it can be cured."

It is difficult though to ascertain the time dimension of belief, and whether belief in a hopeful outcome existed prior to seeking their diagnosis.⁽⁵⁾ Some patients suggested otherwise:

P. "They do miracles nowadays. When I first thought I had cancer I thought that was it. Finished. But as you see here I am as well as ever I was."

S.B. "What made you think of cancer as so bad?"

P. "I just thought if you got cancer there wouldn't be any betterness. I always thought of people wasting away to nothing. I'm not like that. In fact I could do with a bit of wasting."

S.B. "How did you come to know you had cancer."

P. "I asked. My own doctor told me it could be a cyst, left from breastfeeding. I think he said that just to keep my mind easy. After the operation I asked Dr. Y. if it was a cyst or not. He was frank with me, he told me it was cancerous."

She had produced her own set of cues - a healthy appearance - which contradicted her beliefs about cancer and so she changed her beliefs. This patient, like all of the others, had had opportunities to learn their diagnosis prior to admission. Their stay in hospital provided opportunities for others to seek their diagnosis and some did so, risking being told that they had a potentially fatal disease. Only a very few patients made any assertive move to seek diagnosis from staff. They were not likely to meet with much success when they did ask. Just as staff dislike being the bearers of bad news, so patients dislike being recipients of it. However some asked.

Patient who sought to establish his diagnosis

Mr. G. had a carcinoma of bladder and had been treated first by diathermy and then went through a series of tests and examinations after transfer to radiotherapy. He asked at a ward round:

Mr.G "Can you tell me why I am having all this done?"

Dr.H "You are having so many tests because we are trying to establish and evaluate which tests are best to do and which are best to leave out."

Mr.G "Yes, but what's the matter with me? When I was in F3 they did something in theatre and the bleeding stopped. But then I got sent over here and had all this done."

Dr.H "We like to be absolutely sure that your bladder problem has been completely treated."

Mr.G "It's not so much me doctor. It's the wife. She's agitating to know you see. She's afraid it might be cancer. I'm not as worried as she is about cancer. In F3 they told me it was a little wart but what is it really?"

Dr.H "Yes, that's quite right. In F3 you had little blood vessels cauterised, the ends burned off. You were transferred over here to have the ulcer area that was left treated externally so that it will be completely shrunk away. New tissue grows over the area then."

Mr.G "I see. Does that mean it isn't cancer after all?"

Dr.H "No, it isn't. It could well have turned nasty if it had been left but it's been caught."

Mr.G "If you tell the wife that doctor I'll be pleased. You see I don't think she would be able to stand it if it was. I'll ask her to come and speak to you."

This was an unusual position. The patient was trying to protect his wife. He implied that he could take it - 'I'm not as worried as she is'. But was he also trying to avoid knowing about his diagnosis or establish the facts?

A discussion with him suggested that he was aware of his diagnosis. His wife had been under severe stress. There had been several bereavements in the family and among close friends recently including a suicide to contend with.

Mr.G "It's just that I don't think she can take any more right now and this is just the last straw."

S.B. "What do you think it is yourself?"

Mr.G "I think it's cancer all right. So does she, but I was hoping she would get a break. I've been trying to tell her it isn't. If the doctor would, that would more or less settle her mind."

S.B. "So were you asking the doctor if it was cancer?"

Mr.G "I think that's pretty certain. But you can appreciate how they feel about it. I think they're trying to protect us. I only hope they can do the same for the wife."

S.B. "So do you think you'll ask again?"

Mr.G "No, there's no need. I know that's what I've got despite what they say and I don't think there's much point in going any further with it. What I've got to do now is get through the treatment."

So, while he tentatively sought his diagnosis he was not prepared to take the matter any further. His primary interest was in his wife's welfare. He knew he had cancer - his transfer to radiotherapy had been sufficient to indicate this - but he did not seek further information about his prognosis.

Other patients, rather than asking 'it isn't cancer then?' which could be interpreted as not wishing to know, asked explicitly. They were likely to have gone through more in explicit questions before ultimately asking if it was cancer, but even then they were not likely to be told. Mr. W. asked initially in the ward:

"What do you think has caused this?"

"Is it anything to do with pneumonia?"

It was not until he met with his consultant that he asked directly if he had cancer.

Mr. W. "What's been the trouble?"

Dr. M "You had some blockage in the wind pipe. This was an ulcer. We hope this treatment will take care of it for you."

Mr. W "Is it lung cancer?"

Dr. M "No, it's not that exactly. There are different kinds of lung condition and yours is something we can do something for."

Such replies were not sufficient to persuade him that he did or did not have cancer, even though cancer was denied. Could it be that it was too bad to tell him? The patient asked the house doctor and included questions about prognosis. He had resolved that it was cancer and now wanted to know if something could be done.

Mr.W "What will happen if this treatment doesn't work? Will you be able to do anything for me?"

Dr.H "There's no reason at all to think the treatment won't work. But anyway there are lots of treatments we can do nowadays."

Mr.W "Is it a kind of cancer?"

Dr.H "There's certainly some suspicion that's what it could become if it wasn't seen to. It's not that far yet so the treatment's pretty certain."

Mr.W "Is that why I get 5? Does that mean I can have it again?"

Dr.H "Different things are treated in different ways. Five's not so bad and you should feel better soon. We don't want to give you too much."

This news delighted the patient. The number of treatments was equated with severity. Only to have five indicated a good prognosis. Not only that, treatment could be held in reserve just in case it was not completely eradicated on this occasion. I saw him just before he was discharged.

S.B. "Glad to be going home?"

Mr.W "Yes. Mind I'm not complaining. I've been well looked after here but you're better out of places like this."

S.B. "What have they said about it then?"

Mr.W "Well they still haven't said exactly what it is one way or the other but I think it's cancer. It's going that way anyway but it's been got early enough for this treatment to put it to rights."

S.B. "Have they said as much?"

Mr.W "Yes, there's no problem as far as I can see. Having five was a real boost."

S.B. "Do you feel the treatment's been a success?"

Mr.W "I don't feel the good of it yet but I was told it goes on working when you're home. That's when you feel the benefits."

S.B. "Are you satisfied with how you've been treated. What you've been told about things?"

Mr. W "Definitely. I think I've been treated fair. You have to ask to find things out but that's reasonable. I certainly couldn't have had it better."

Mr. W. had obtained the information he sought about his diagnosis and prognosis. The fact that he was only having five radiotherapy sessions as well as the fact that he was not having to come back for follow up added to his optimism about the future. Despite the doctor's efforts to persuade him otherwise, he was sure that if his illness was not cancer, it would have soon turned to it. Unfortunately his interpretation of what he was told and the optimism^{ism} it engendered were not justified.

Patients aware of diagnosis who sought prognosis

Miss A. was an example of a patient undergoing the process toward ultimate realization that her disease had spread and would prove fatal. She was already aware of her diagnosis and presented with severe leg pains. She described how three years previously she had felt a breast lump and had suspected cancer. The operation had confirmed her suspicions and she had a full course of radiotherapy after a protracted illness complicated by a pulmonary embolism. Two years later there were several more lumps which had been excised. Although she had been informed that these were benign, in fact her case notes indicated lymphatic spread.

Miss A "Now I'm in to see about this leg. It's been very sore."

S.B. "What's the cause of that then?"

Miss A "I'm very disappointed that this has happened now. I thought I was beginning to get over everything. I tried to find out what's behind it."

S.B. "Have you asked?"

Miss A "Dr. H. said it could be some reaction to the earlier thing. Reaction spread through the blood stream. I'm not sure what he meant."

S.B. "Do you mean associated with your breast?"

Miss A "Well I wasn't sure if it was that or the actual treatment. I'm not afraid of cancer you know. Even though my mother died of it."

She described her mother's four month illness and eventual painful death. She had now lived for three years with this illness. She had watched television programmes about it, showing the value of early detection and surgery. She believed she had been 'caught early' and her tumour had been completely removed. However, she was aware of the possible outcome.

Miss A "If I die I won't be afraid. I've got a strong faith, I know where I'll be going. If they said I've only six months to live I would just have to accept it."

Although she said this, she did not ask it and, of course, no such information would be offered. She described how her life had been affected by the psychological trauma of mastectomy. She had been a keen swimmer but stopped because of her disfigurement. She had also stopped kissing her nieces, nephews and Sunday school children 'in case I passed anything on to them'. She was convinced however that her earlier excisions had shown no spread. On subsequent days she returned to the theme that she could not understand how her leg had become painful and what was the basis of the pain. She latched on to the idea initiated by the House Officer, that it was associated with treatment. It was extremely painful and she was unable to weight bear.

Her hopes were raised when it was later suggested by the consultant that it may be 'something to do with your veins' causing the pain and swelling. A surgical opinion was sought and some tests

carried out but these proved inconclusive. Nevertheless they boosted her hopes temporarily.

It was eventually decided she should have a palliative course of radiotherapy and then be sent home again.

During this time she was still unsure about the cause of her leg pain.

Miss A "At first I thought it was rheumatics or arthritis but Dr. H. said it was the side effects of the first course of treatment. Why they should give me more beats me. So long as it gets rid of this pain."

She had difficulty in reconciling giving more treatment with the fact that the nature of her illness remained uncertain. However she was not yet prepared to face the truth. While in the ward other patients had upset her by describing patients who were crippled after mastectomy and another whose husband had died after a leg amputation for bone cancer.

Miss A "They talk about these things too much. Every case is different so I don't think I'll be like that."

Her consultant came to see her and told her they were hoping the treatment would ease the pain soon and she would be transferred to another hospital to convalesce. She was unhappy at the thought of yet another spell in hospital but accepted she was still not well enough to manage alone. She continued to claim uncertainty about her leg problems and became increasingly concerned about the continuous pain.

Miss A "I can't understand how the pain isn't any better."

Dr. H "The treatment won't work right away. That's why we want you to convalesce."

Miss A "Has it gone through my blood stream or something?"

Dr. H "It's pain from the spinal nerves. They branch out and one of them is playing up. That's what's causing you to have a sore leg. It's really the spine. That's why we had a bit of trouble getting to the root of it."

She did not want to remain in hospital. She also realised that there was a possibility that she would not be cured.

Miss A "I'm not too badly off. If I'm not cured I can get somebody in to help me. I would be prepared to go into hospital when the time comes but I would rather be in my own home just now."

She was faced with conflicts about whether her illness had spread and the possibility of cure but she could not discuss these with staff in case they told her. Despite her protestations that she was not afraid, she was not ready to face all of the facts. She was discharged home, no bed being available elsewhere, still not having ascertained for definite whether the disease had spread.

She reported for the three week follow up still suffering severe pain. Disappointed with the result, the consultant suggested a possible surgical treatment. This was pituitary ablation, with the aim of inducing hormonal control of the illness. On readmission she said:

Miss A "He asked me if I would be prepared to undergo some tests then wait for surgery. I asked him about the pain and he said this operation should control it, something to do with different hormones. I said I would be prepared to accept anything. He is a great man."

The following week she was admitted for tests which, she was assured, showed everything normal. Pain was her over-riding concern, she was aware it could become worse.

Miss A "I've been on tablets but I don't want to take them too often. I was offered injections but they knock me out. If it gets worse later I want them to fall back on."

A different house officer admitted her. She was concerned about the prognosis and the outcome of surgery, indicating she now knew that her illness had spread.

Dr. K "She was asking about the success rate of this thing. I think she asks too much for her own good."

S.B. "What did you tell her?"

Dr. K "I told her that Dr. A. thought there was quite a good chance. Mind he told me there's only about 14 per cent success but figures are quoted up to 35 per cent. It's about all there is left to offer her. There's no point in making what's left miserable."

It was agreed she should undergo surgery.

"Dr. A. told me the back pictures were very encouraging so he's going to do the operation. I can only hope that it relieves the pain and slows up the spread."

She volunteered that she had learned that cancer had spread. She reflected that she had been suspicious in her previous admission but had not actually asked anyone. On this admission she had decided to confirm her suspicions.

Miss A "Last time I was in you asked me if I thought nurses should discuss illness with patients and I said no, they never had time and the young ones didn't know enough."

S.B. "Yes, I wanted your opinion because I knew you had been talking with some nurses."

Miss A "Well now I think different. I thought it should be left up to the doctors but now I think nurses are more sympathetic."

She described how she had talked with the ward sister and asked about her condition. This nurse described how her illness had spread to both legs and the hopes that the operation could alleviate the pain and contain the disease. She did not promise cure however.

Miss A "She was so kind and patient. Dr. A. gave me no idea it had gone so far. He just put it down to hormones. Though I suspected, she was prepared to talk about it. I was grateful for that."

After surgery which proved a more drastic affair than she had anticipated, her pain was alleviated and she began to walk again. This was taken as a most encouraging sign that the illness had abated although the chance of cure was recognised as slim.

Miss A "I lived in fear after the breast operation till I saw that T.V. programme. Then I read the article in Readers Digest about this operation. I feel my life has been given back to me twice now. Life has taken on a new meaning. It's richer and I've got more faith than ever."

S.B. "Have you any worries now?"

Miss A "Only about the pain. I've never had such pain before. Now it's relieved I feel so well. But I'm worried in case it comes back again."

S.B. "Do you think it's cleared up for good?"

Miss A "Well I feel this relief must have been meant for me. I must have a job to do otherwise I would be under the ground by now."

S.B. "So do you think it's cured?"

Miss A "All I know is if I hadn't had this operation it would have spread so much I would have been dead in a short time. Cure is hard to believe, I hope so."

S.B. "Have you asked about the future?"

Miss A "No. I want to take each day as it comes. I know it's just being held in check. It can start up again any time. But every day is wonderful and I'll just keep on praying."

Miss A. had gradually come to acknowledge that her disease had spread and that the relief she now experienced could be temporary. She was however relatively hopeful about the future, relying on her faith and the good fortune she believed she had had up till this point. This patient showed clearly the limits to which she was prepared to go in ascertaining her prognosis and demonstrated the transactional nature of information and awareness. Her interpretation of events varied with the kind of interpretation she was attempting to construct and maintain. The idea that her symptoms were due to something other than spread was gradually replaced by an awareness of a worsening prognosis, which she eventually confirmed by asking. The alleviation of symptoms after surgery however resulted in a renewed optimism extending to a hope for cure, but with awareness that symptoms could flare up again. This patient also demonstrated that while hope may rest in cure, she was equally hopeful that the pain she suffered would be relieved and that she would not be subjected to the painful death experienced by her mother. The

alleviation of her symptoms gave her grounds for optimism. Hope did not always lie in cure, some patients knew there was no absolute cure and they rested their hopes in control of the illness.

Mrs. M "I don't think there's an absolute cure. But it lies dormant and you can keep it under control. You just have to hope it doesn't flare up again."

Of course an assurance of cure would have been welcome. Not all patients could have it however, nor believe that this would be the outcome.

Patient knew diagnosis and attempted to establish that she would be cured.

Miss D., a fifty-eight year old spinster, had carcinoma of rectum. She had learned her diagnosis after a series of surgical attempts to control her disease. Her initial thought was that 'it's just piles' and indeed a haemorrhoidectomy had been performed. Worsening and persistent symptoms of bowel irregularities and bleeding had resulted in another admission and finally an abdomino-perineal excision of rectum was performed. Her latest admission to the surgical ward had shown a local recurrence which was now to be treated by radiotherapy and chemotherapy. She had originally rejected the idea that it could be cancer until the persistence of the illness coupled with referral for radiotherapy produced realisation.

Miss D. "I got really fed up. Mr. A. said after the last two operations I wouldn't need any more but then it came back again."

S.B. "What was the reason for the operation, did he say?"

Miss D. "He told me at first it was just piles, then there was a bit left and it turned into a growth but only a small thing and it was completely removed. I'd always had a fear of cancer you see so I didn't think at first that's what it was."

S.B. "Did you ask him?"

Miss D. "Not until I went in the last time. I thought it might be - in fact I was petrified."

S.B. "What made you think it was that?"

Miss D. "I don't know really. At first I thought it was only some blockage. I suppose when it still didn't clear up I got suspicious, especially when this pain started."

S.B. "So you asked him?"

Miss D. "The last time when these little bumps came and there was more bleeding. I got it out into the open. I said to tell me if it was cancer and it was then he told me he he didn't want to do any more operations. You see I thought cancer was final and there was no cure. But he said this new treatment was worth trying instead of an operation. He had put me through enough."

S.B. "So you knew it was cancer without being told?"

Miss D. "Yes I did - maybe not know. I was always hoping it wouldn't be but getting sent here just confirmed it all the more."

She was transferred for a course of radiotherapy coupled with 5 Fluorouracil. The prospect of cure was remote but hopefully the treatment would arrest or slow the progress of the disease. On admission her aim was to learn something of her prognosis and she confronted the house officer on admission.

Dr. H "This new one in 1, she's going to be a right handful. No sooner was she in the door than she's telling me she knows she's got cancer and can I cure her."

S.B. "What did you tell her?"

Dr. H "The truth. I told her we would try, that was why she was here for us to cure her."

S.B. "Did she accept that?"

Dr. H "Not her. She's neurotic. She said was I sure there would be a cure. I told her we couldn't be absolutely sure but the very worst she could expect was three or four years."

S.B. "What did she say to that?"

Dr. H "She got even more upset and crying like. I suggested she might see the chaplain or the psychiatrist."

The patient did ask to talk to the Chaplain and she was also referred for psychiatric help. While this was happening Miss D. had to go through some diagnostic tests to assess the extent of local spread. These tests were explained in the routine manner.

Dr. S "We want to do a few tests, Miss D. just to get us ready for this treatment. You'll have blood tests and we want to examine you under anaesthetic just to make sure all is well to go ahead."

She was anxious to know the results. She could not wait until she saw the consultant and asked at the ward round.

Miss D. "What did the tests show up?"

Dr. H. "Do you mean in theatre?"

Miss D. "Yes, yesterday."

Dr. H. "We don't get the results here. The examination was done by the urologist, we don't get the results up here. You'll have to ask when you go downstairs. O.K.?"

Miss D. "What were they looking for?"

Dr. H. "Just to check everything was all right. All this surgery has taken a lot out of you, you know."

Miss D. "I was wondering, if it's been removed once, can it be removed again?"

Dr. H. "Yes, it can be done again. But that's not usually necessary. O.K.?"

Miss D. "What about starting the treatment now?"

Dr. J. "You'll see Dr. S. on Monday and probably get started after that. O.K.?"

She was anxious to know all the details and was by far the most persistent patient observed in the study. She had learned that other patients were not having injections along with their radiotherapy. Why should she be different? Was she worse? She asked.

Miss D. "Why am I getting injections as well?"

Dr. H. "That's the best approach to this sort of thing."

Miss D. "Does that make it any better or what?"

Dr. H. "Yes, it makes it more sensitive to radiation. In your case we think this would be the best approach."

Miss D. "Does that make a cure more likely?"

Dr. H. "Yes, it does. I would expect there to be a good chance. We can't say 99 in 100 but the odds are definitely in your favour."

Miss D. "But if it doesn't work, what will happen to me?"

Dr. H. "Oh, you'll get a lot of benefit from this. We've every confidence it is going to be very favourable."

She sought to reduce her uncertainties about the outcome and also expressed some of the roots of her fears - about the consequences should the treatment not work. The doctor was not prepared to explore this probable eventuality however, reinforcing the beneficial effects of treatment. As the house officer said:

"I'd not give her any better than a fair chance. But I gave her more favourable odds than she justifies. It's not definitely hopeless."

In the ward she sought reassurance from the other patients and talked a lot about herself as a means of relieving distress. Since she was having new treatment she regarded this as favourable but still she did not have the certainty she sought. Her room mates became upset by the persistence of her outbursts and questioning.

"Every time we begin to talk about anything she turns the conversation round to cancer and her cure. She's driving us all potty. It won't be her needs the trick cyclist, it will be us. I don't know what she expects us to tell her different from the doctors."

She found her sessions with the psychiatrist upsetting and she was noticeably disturbed on her return to the ward to the extent that the other patients attempted to persuade her to stop seeing him. His approach which he reported back to the house officer had been to try to help her face the existential concerns associated with her poor prognosis. This was entirely contradictory to the approach of both nursing and medical staff in the ward, who were seeking to avoid this realisation and engender hope of a favourable outcome. Reconciling these antithetical approaches increased Miss D.'s apprehension and anxiety.

Miss D. "When he (the psychiatrist) asked me what I thought Dr. H. meant by saying I had quite a good chance of cure I felt I was falling through my chair then hitting the ceiling."

S.B. "Why do you think you felt like this?"

Miss D. "I just don't want to think about it any more now. He makes me think of the worst that could happen. It's too upsetting."

The psychiatrist was aware of the conflicts, engendered partly by the conflicting information available to her from her own previous treatment and symptoms compared with that given by ward staff. The Chaplain was also aware of this.

Chaplain: "She's seen so many doctors now and been told so many different things she doesn't know what to believe any more. The information she's been getting is conflicting with the objective facts."

She stopped going to see the psychiatrist and it was arranged that she could ask to see him should she change her mind. She never did.

"I'm just a very mixed up woman. I don't know what to believe any more."

She still desperately wanted to believe in a cure. I saw her again at the end of her course of treatment. She had stopped asking so many questions but she was still in doubt as to whether a cure could be obtained.

Miss D. "They tell me they are quite pleased with the results. It's new so they've given me good hopes for it."

S.B. "How are you feeling about things now? You were very worried at one time."

Miss D. "I'm a bit more relaxed now. I've been sleeping a lot. But I'm still left wondering if it's going to be all right."

S.B. "What do you think now?"

Miss D. "I think there's a good chance but it's not definite. At least I know there's always something else they can do if it does come back. Of course I'm hoping it won't."

S.B. "Have you learned all you want to know about it?"

Miss D. "I think the doctors have told me as much as they can right now. I would have liked more definite information that it was cleared up but it's not possible to be that certain apparently. As they've explained it though all I can do is hope for the best."

While this patient was sorely troubled while she was in hospital, she was much more hopeful of her prognosis when she was discharged than when she had been admitted. Again motivation to seek and avoid information according to the desired construction of reality is apparent in the process of adjustment to the illness.

Awareness and Desire for Information

The foregoing presentation showed that patients did not exist passively in a sea of information. They were actively and selectively perceiving or ignoring, seeking or avoiding. Their desire for information together with its interpretation depended, at least partly, on particular beliefs about cancer and conceptualisations of the illness. Selective seeking and avoiding was both a product of and in turn fostered and sustained a particular interpretation and adaptive strategy in an effort to resolve the problem of having cancer. Some patients sought to avoid becoming aware, preferring rather to maintain uncertainty about their illness. Others were prepared to seek whatever information was available to extend their knowledge - up to a point. They would only go so far. While seeking to learn their diagnosis and the extent of their illness they drew the line at seeking positive information that it would prove fatal.

There were limits to the success of these different forms of adjustment. Limits were imposed by staff in the amount of information they would formally convey to patients. This assisted patients who did not want to know to avoid realisation of the facts and to construct as hopeful a picture as the interpretation of other information would permit. Despite a desire not to know, the strength of information could be such that it was not easily ignored or rationalised into an optimistic framework. For instance a worsening prognosis indicated by repeated admissions and treatment, persistent symptoms and increasing

debility were not easily discounted. Although patients searched for and focussed on signs to sustain a hopeful outlook, the flow of information to the patient, although sometimes contradictory, could not always be appraised in accord with a hopeful interpretation. This may happen for a time or be interspersed with doubts about the appropriate interpretation until the accumulation of evidence was so overwhelming that patients could not rationalise it away or ignore its significance.

It was only when the weight of evidence built up to the extent that alternative explanations were no longer possible that patients, reluctantly, became aware. Awareness therefore did not come suddenly but gradually and was revealed in how patients talked about their illness.

"I'll just have to hope they can do something for me now. I've had it all these years and it's just flared up again. I don't know what set it off. I only hope it won't be too late but I've a feeling I won't get better. There's no signs of improvement."

Patients varied in their response to information. Moods fluctuated according to the relative weights of information which could be regarded optimistically or pessimistically. Patients showed anxiety and depression but some came to awareness of the inevitably fatal outcome of their illness without giving up hope.

"I know they can't cure it but there's still things they can do to keep it at bay. I'll go on fighting as long as I'm able."

"Maybe I'll come in again with it someplace else but they'll not stop it now. I'm having to come to terms with it in my own way."

It would be wrong to say that patients accepted their illness but some showed hope. Not hope of cure but hope that the illness would be contained, that death would not be painful, that they would continue to live for as long as possible.

"I just take each day as it comes. When I wake up in the morning I'm thankful for another day and hope I'll live through it."

And so, while some patients wished to avoid becoming aware they ended up knowing the facts of their illness. Others were in a position of wanting to learn more. The next chapter deals with how patients sought information in the formal network while they were in hospital.

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CHAPTER 13INFORMATION SEEKING IN THE FORMAL NETWORK

When patients asked about their illness it is an indication that they want to know. That many do not ask may be explained either as not wishing to know or being unable to ask because of the constraints imposed by the manoeuvres of staff. Patients commented on facts like the absence of privacy, the business of the wards and the limited nature of the interests of consultants at review clinics as reasons for not asking. Asking was also inhibited by the information volunteered to patients suggesting that their illness was nothing to worry about and the outlook was favourable. The management of interactions by doctors and nurses with patients served to curtail the likelihood of asking while the responses given when patients did ask added to difficulties encountered in finding out the truth. Therefore unless patients had a very definite desire to know, they were not likely to learn much by what was formally conveyed to them.

"He wasn't very specific in what he told me. I asked what it was and he put it down to pressure but not what was causing it. I'll just have to ask my own doctor when I get home. He'll tell me better what's at the root of it."

Patients like this did not press their questions. They said they wanted to know, and suspected cancer, but were not prepared 'to be a nuisance and take up their time'. Some believed that the doctor would be unlikely to deliver a fuller explanation, that nurses may not know and in any case were not in a position to tell, or that some uncertainty was still associated with their condition. Some patients also appreciated the difficulty of the problem. They realised that not all patients wanted to be told and so the doctors guarded approach was seen in this light. There was some sympathy.

"I wouldn't fancy their job. It can't be easy them doing their best for people and having to face them with this kind of thing."

Others however found it difficult to understand why doctors tried to deny cancer when the patients knew full well that this was the diagnosis.

Of course, if they knew they had no need to ask. However some wanted to establish their knowledge with others.

"I wasn't actually told it was cancer but it's obvious that's what it is. But when I said to that doctor downstairs I knew what it was he tried to tell me that it wasn't, it was some kind of wart. Now what's the point of that, it kind of belittles you."

It was recognised that the doctor could try to protect the patient from the truth.

Some patients were content to interpret the euphemistic labels offered in accord with maintaining uncertainty about the illness or with a belief that the illness was not cancer. Others recognised such explanations for what they were.

"He said it was a wart but I know it's far more serious than just a wart."

Patients who had already decided that they had cancer, and had sought to confirm this, generally did not trouble to establish the point further.

"If that's how he's going to call it, it doesn't change the fact that it's a malignant thing."

Believing that they would not be told any more, there was no point in going on. However patients who did want more information could ask staff. They had to learn how much they were prepared to divulge and how to ask.

Asking About Diagnosis

Discussed earlier were the ways in which doctors and nurses

responded to the kinds of questions patients asked about their diagnosis. It was apparent that patients were more likely to ask questions of a general form "What is it?", "What's causing this breathlessness?" than they were to ask directly if it was cancer. Staff were armed with stock replies to such questions and patients would not be told that they had cancer. If they wanted to find out, to have all uncertainties eradicated that the illness was not something else, then they had to press further. They could ask for clarification but they were still unlikely to be given a full explanation.

P. "Yes, but what's causing the pressure?"

Dr.S "It will go down very quickly with the treatment."

P. "But what's causing it?"

Dr.S "Don't you worry about that. It's just a swelling and it will be relieved shortly."

The doctor could expand on the explanation and tell "We're not exactly sure what's causing it - it could be one of several things", "It could go nasty", which still did not disclose malignancy. Because of the evasiveness of responses, patients had to become more forthright themselves.

Mr.H "This pain is getting worse. Is it some kind of indigestion?"

Dr.H "Well it's certainly more than a prolonged bout of indigestion
Mr. H. But the pain should subside once the treatment gets a hold."

Mr.H "What's causing the pain?"

Dr.H "It's glands pressing on a nerve. That's what makes it seem so much worse than it really is. It will go away in time."

Mr.H "What kind of gland? Could it be a cancer type of thing?"

Dr.H "No, nothing like that. Just one of those things that happen. We don't know what triggers them off but we can do something for them."

Even greater explicitness did not result in having cancer confirmed. If the question was not ignored, responses were likely to remain ambiguous while holding an allusion to a positive outcome. The response was likely to suggest that the illness was only potentially dangerous, though the fact that the danger was cancer was unlikely to be made explicit.

"You could have had problems if it hadn't been caught and seen to."

At times cancer was denied:

"Cancer covers all sorts of things but what you've got doesn't fall into that category."

On the rare occasion when cancer was unequivocally confirmed, a hopeful outlook was simultaneously implied.

"Yes, it's cancer. But you've had it for fifteen years and see how well you have kept. This is just a temporary setback."

To get this far patients had to be very persistent or give evidence that the illness was cancer which could not be challenged. Patients knew that going to a Marie Curie establishment meant that they had cancer. Openly confronting the doctor with this information meant that he could not deny it.

Asking About Prognosis

Patients were not likely to ask about prognosis in the sense that they wanted to know if their illness would prove fatal or how long they had to live. Rather they wanted to know whether 'the treatment had worked', whether their 'troubles were over'. Many patients wanted to learn that they had been cured - at least this was what they hoped to learn - rather than details of the extent of their illness or the probability of relief.

Patients were interested in the alleviation of symptoms which,

in itself, was regarded as a significant indicator of the efficacy of treatment. Indeed this was so, but this was by no means equivalent to cure. However patients at this time were anxious to learn about local effects - "Will the swelling go down?", "Will my leg decrease in size?", "Will this breathlessness get any better?" and patients were reassured of current manifestations of success or that "it will take some time to be effective".

Where there were no local manifestations of the illness patients had recourse to the kind of question open to any patient "Will I be O.K. now?", "Is that it all clear?" to which plausible responses conveyed the optimism patients may have been seeking.

Those who knew their diagnosis and were being treated for the first time tolerated hopes that "they got it all" and that "the treatment will take care of it" which co-existed with fears that perhaps it was not removed completely at surgery or that the treatment may not prove completely effective. Patients were aware however that the best chance of cure was this first treatment attempt. Thus, while undergoing treatment they had some grounds for optimism which was reinforced by what was volunteered by staff. In such circumstances they were not likely to jeopardise their optimism by asking more explicitly about prognosis.

Some patients did want to know more about the extent of their illness but it was apparent that how much they wanted to know was indicated in the type of questions they asked. "Is that me all clear now?" or "Are you pleased with the X-rays?" indicated that the patients were hopeful at the end of treatment that there was cause for optimism.

Some patients of course did ask about the significance of new signs or symptoms, particularly when diagnosis was already known and patients sought to establish that the illness had spread. This was

particularly evident among patients with metastatic breast cancer when the significance of lymphoedema or pain were called into question. It was difficult to understand how pain could manifest at sites so removed from the original lesion. "Has this anything to do with my earlier treatment?" Patients with lymphatic disease were aware of the significance of new bumps and sought to establish whether these were 'nodes' or some other reason lay behind their appearance. One patient sought to establish whether the swelling which had occluded her ureters and caused urinary retention was a 'tumour' or another 'gland'.

Mrs. M "What is it down here doctor? Is it a tumour now?"

Dr. G "No, it's not a tumour. It's the glands again. Remember when you had your groin treated for nodes before? Well these extend all the way up inside your abdomen. It's a gland been pressing."

Mrs. M "It's not a growth then?"

Dr. G "No, it's not a growth. It's a gland and it's pressing on the tubes from the kidneys to the bladder. The treatment's reduced the swelling again."

While patients sought to establish that the illness had spread and the nature of the spread this was not equivalent to asking whether there was any chance of cure. The replies which denied that cancer had spread were variously interpreted. Some patients took assurances to mean that the outlook was optimistic - after all if there was no reason to think otherwise - that they may be among the lucky ones - then why not accept what was said? This was all right so long as contradictory cues were not available. When patients were assured that what they had was not spread and they knew otherwise, then this had the effect of making them believe that it was so bad the doctor could not be honest. And they were correct.

Patients did not go so far as to ask if they would die. Patients were observed to bring up the subject of dying with nurses - making

statements that they knew they would die but only one was known to ask while another asked "I wish they would tell me how long I've got". Neither patient was known to have asked again and of course they did not receive the information. Another patient asked about whether she would be cured but cure was not promised while an optimistic interpretation was placed on the probable outcome.

It was difficult for patients to find out about their prognosis. The attempt by staff to paint an optimistic picture was guided by an assumption that patients wanted it this way. Certainly some did, but for those who did want to know the details it was difficult for them to do so. Some did of course learn as much as they wanted to know. When patients with lymphatic disease asked about the meaning of a new swelling they were likely to be told that it was another 'node', at least if they asked the consultant. However many patients were not able to learn as much as they wanted to because they were not able to establish with those they asked that they really did want to know or that they could be counted upon not to react badly.

Indeed patients had few resources by which to establish unequivocally that they wanted to know the facts; this meant that the status of their questions remained uncertain.

Did Patients Really Want to Know?

What lay behind patients' questions is important in the light of beliefs held by doctors and nurses that although patients ask, they do not necessarily want the facts. In the study, only two patients were observed where this appeared to be the case. One patient was an out-patient and was described by her consultant as 'one of those dreadful patients who attacks you for information and when you do tell her something she turns round and doesn't believe

a word of it. She's quite ga-ga.'

She was being treated for lymphoedema arising from metastases from previously treated breast cancer. She had been informed of her malignancy at the time of her breast treatment but later volunteered:

Mrs. T "What the devil this is nobody knows. They turned me inside out and took a little piece but it wasn't cancer. They've even examined my brain (brain scan). I think it must be a vacuum - (laughs)."

In fact, she had been reassured at the clinic the previous week that she did not have cancer.

Dr. F "Well it's obvious she doesn't want to know. She's a sensible woman - no, not sensible but intelligent - and if she wanted she would have a pretty good idea. It's obvious she doesn't want to know and she keeps on about it. I would never tell a woman like that."

At the next review clinic the patient followed the same tack.

Mrs. T "I wish they knew what this was. I get worried not knowing."

Dr. F "Well you must be a special one. Just don't worry and get through the treatment."

Mrs. T "It's getting bigger you know. He knows (the consultant) that it's getting bigger too. When will it go away?"

Dr. F "We'll know better at follow up in three weeks. After that we'll have a better idea if it will go down."

Mrs. T "Well it didn't go down the last time any. Still I suppose I'll just have to wait and see. Mind you, if I'm so special if you find out anything from treating this I'll be sending you a bill for services rendered (laugh)."

Despite her mild protestations she was not really asking for information. She had done so previously only to question the facts and search for a more acceptable answer. In the meantime she believed that her illness was a mystery. The symptoms were pronounced and she was complying with treatment but at this stage she was maintaining a strong defense against realisation by imputing uncertainty where, in reality, none existed.

The other patient, described on page 264 asked about the possibility of cure. The information given by the house officer had

been more optimistic than the facts warranted but fell short of promising cure. Thereafter the patient showed a high level of anxiety and it can only be interpreted that while she may have wanted to know the facts she was not ready to face them with equanimity. Of course her problems were increased by the contradictory approaches taken by the psychiatric service and the ward staff. In the absence of knowing the precise nature of her original question it is difficult to know exactly what the patient asked but the persistence of her questions indicated that she did want to know something although this could have been so that she too could question what she had been told initially, and arrive at something more acceptable. Her decision to discontinue the psychiatric consultation with reliance on the relatively reassuring information she was given from the ward staff certainly suggested this could be the case.

Data obtained from discussion with other patients after they had been observed to ask indicated that their questions were an accurate reflection of the information sought. Patients did not ask questions out of the blue. They had good grounds for doing so. Indeed, by the time they asked they were almost certain of the facts themselves and wanted to abolish the remaining grain of uncertainty. Those who asked did so because they wanted to know, not because they wanted reassurances. If patients did not want to find out they would not have risked asking. For this reason it was important to listen to how patients asked and what they asked.

As described, questions were not always explicit in the sense of asking for a diagnosis of cancer. However just because patients did not use the word cancer, this was not equivalent to saying that they were not asking. In an environment so loaded with cues patients who sought to avoid realisation would not have asked even general

questions about cause or the meaning of symptoms. When patients were attempting to avoid awareness they told nurses - "I'm glad it isn't cancer", they would not ask questions about their illness.

Patients who asked wanted to know. They had had to come to a decision to ask and were prepared to hear. In fact asking sometimes amounted to an acknowledgement that they already knew. Euphemistic replies or denials did not alter their beliefs about the nature of the illness. Rather, they created a degree of mistrust and anger mingled with sympathy for the staff for the job they had to do.

The status of questions about prognosis created greater difficulties. It is not unusual for any patient to ask at the end of a course of treatment whether the treatment has been successful or whether all is well. This gives no indication of what patients know. Similarly patients asked about tests because they wanted to know what would be involved or whether it would be painful or about the results as a formality; "Have the results come through" rather than the significance of the results in terms of their prognosis. Patients who were aware of the significance of facts sought this information more explicitly. For instance, one patient with carcinoma of cervix was not satisfied that the explanation of a kidney X-ray was 'routine'. When a faulty film was taken and the examination had to be repeated, this interest alerted her suspicions that her kidneys may be affected. She had to become increasingly specific after asking about the reasons for the X-rays, why it was being done again, what it would show, to asking a nurse 'has it spread to my kidneys now? Is that what they think?' Questions showing this degree of specificity about the characteristics of cancer indicate that the patient is aware of the diagnosis and is seeking information about the extent of the illness. Questions indicated how much the

patient wanted to know about prognosis. To ask about extent is not to ask about fatality.

As patients gradually acquired information, seeking partial information contributed to the ongoing process of establishing a prognosis. Some patients came to know the outlook but only after gradually accumulating information, through asking different kinds of questions which built up a mosaic about the illness. Therefore the status of patients' questions about prognosis had to be set within the context of previous behaviour. As in the case of diagnosis, patients would not ask questions specific to prognosis in cancer unless they wanted to know. Their questions reflected their level of awareness. Patients asked when they were ready to know and anxiety or depression cannot be taken as equivalent to not wanting to know.

Patient Strategies

Hospital staff were able to use tactics to limit the amount of information given patients. Patients were not observed to be similarly agile in developing strategies to obtain the information they sought. Of course they had less practice in developing ways of getting around staff. In fact few patients even went so far as to persist in questioning when they felt information was denied them. If they did they tended to be labelled as 'troublesome'. One patient managed to attract this label by 'making a fuss' at out-patients. She had indicated that she knew she had cancer and when the doctor avoided the term she became angry and screamed out so that all of the other patients could hear. As a consequence it was recognised that it would be better not to try to hide the nature of the illness while she was in hospital and to try to deal with her questions by

acknowledging her awareness. While this did not result in the patient being given any more truthful information about her prognosis when she sought it, at least replies were consistent with awareness on the part of staff that she knew her diagnosis. However she was tactfully requested not to be so open about her illness in front of other patients.

Another patient learned of her diagnosis after she absconded. Her behaviour was not planned to obtain this information. Rather she was frightened by what she saw about her. Her rejection of treatment however resulted in her diagnosis being imparted by both her General Practitioner and hospital doctor in an attempt to make her realise the necessity for treatment. No patient refused treatment specifically as a bargaining tactic to gain information.

One patient managed to learn her diagnosis after informing the doctor that she knew she had already had a cancer successfully treated. She impressed on him that she had been recently widowed and had affairs to settle. It is not certain whether the fact that the patient had already had a cancer treated successfully and provided the optimism which disclosure was considered as destroying or whether the patient saying she had affairs to manage resulted in disclosure. Both were reported as grounds for telling and the patient managed to remove uncertainty that she did wish to know. Her request was limited to diagnosis, but later she sought prognostic information.

The only obviously used tactic to gain information was to ask different members of staff the same questions. This was facilitated by the consultant seeing the patient away from the ward and the house officer and nursing staff seeing patients in the ward. Patients could therefore ask different personnel without this knowledge being shared. This was successful in obtaining contradictory information

when non-routinised replies were used and patients drew their own conclusions. Otherwise patients learned little when met with consistency.

Few patients were devious in their attempts to acquire information, not many even went as far as to be persistent in their questioning and none invoked their rights to be told. In this way cancer patients are markedly different from the tuberculosis patients described by Roth.⁽¹⁾ However they were not completely constrained by staff in obtaining the information they wanted. Patients were able to rely on informally available cues from hospital staff as well as information which could be gained in the informal network. These important sources of information are discussed in the next chapter.

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CHAPTER 14 THE INFORMAL INFORMATION NETWORK

This chapter describes how patients made use of information other than that formally and intentionally imparted by doctors and nurses. Informally available information includes verbal and non-verbal cues from hospital staff, other patients, relatives and friends as well as clues and symbols available to patients by virtue of being in hospital.

Doctors and nurses, in their efforts to avoid revealing information to patients about their condition, at times engaged in ploys attempting to minimise cues and counteract the real facts. Similarly relatives and other visitors as well as patients themselves were selective in the information they imparted and to whom. There was a limit however to the extent to which informal information could be controlled.

Of course, what constituted information depended on the patient's particular interpretative framework. Ostensibly the same events were selectively perceived and held different meanings depending on whether the patient was suspicious and attempting to establish a diagnosis or prognosis or avoiding realisation of the facts. The same may be said for how patients interpreted formally given information. Some of the cues available to patients prior to admission were discussed in Chapter 12. The current spell in hospital provided further scope for those seeking information.

Hospital Staff as an Informal Source

It was not evident that hospital staff other than doctors and nurses provided information to patients. Certainly others could have done so. Radiographers for instance reported being asked by patients about the reasons for treatment and particular X-ray examinations. They reported and were observed to impart nothing beyond the routine

responses used by doctors and nurses in such circumstances. Porters and cleaners, physiotherapists, social workers and clergymen also apparently imparted nothing of significance about the illness. Indeed a deaconess and chaplain both reported how they felt that they could have been more helpful to some patients who expressed faith had they been more open about the illness and future. However, their awareness of the restrictive information giving practices employed by doctors and their own informal status in the wards resulted in them also avoiding open communication. Patients did not ask these hospital workers for information about their condition and apparently they received none, although non-verbal cues may have been involved.

Doctors and nurses on the other hand informally provided information to patients within the formal communications already described as well as non-verbally. Those who were suspicious could learn something from what they were not told. The fact that the illness had not been given a clear diagnostic label or no recognizable diagnosis at all was an indication to some that it must be something not openly talked about - namely cancer. Thus, although descriptive or euphemistic terms were used, these did not always mislead patients who were already suspicious. Added to the other cues available, patients were able to infer malignancy:

"Maybe it looks like warts like he said, but I know it's more serious than just that."

On the other hand, patients not wishing to know could take the labels volunteered, like 'ulcer' and 'blockage' at their face value. Terms like 'suspicious cells' or 'it could turn nasty' need not necessarily imply malignancy while referring to its distinctive features. The illness could remain uncertain, reinforcing that 'they are not sure exactly what it is' permitting a hopeful conception that it may, in

the end, prove not to be cancer. The same words thus held a variety of meanings for different patients.

While doctors and nurses rarely told in the formal sense, nevertheless what they said could be interpreted in such a way as to confirm suspicions. Telling therefore depended not so much on what was said as on how it was interpreted. This depended largely upon the patient's interpretative framework.

Similarly, the behaviour observed at times among both nurses and doctors, when they avoided answering patients' questions by appearing not to hear or by giving some response which did not fit the question, did not formally convey information. The fact that patients realised that staff were avoiding the issues posed told them, in this context, that there was something sinister to hide. Suspicious patients then drew informal conclusions about the nature of the illness or its severity.

As well as verbal behaviour being a means of obtaining information informally, non-verbal behaviour could be equally telling. One patient for instance, admitted because spinal metastases had resulted in paraplegia, was subjected to three examinations of her abdomen in rapid succession. The neurosurgeons, who had been called to examine the patient, suspected palpable liver metastases and so considered the illness too advanced to warrant surgery. The consultant and then the house officer, neither of whom had previously noted the mass, came to check for themselves. This new attention to her abdomen which had formerly not featured in her illness, together with the information that 'no surgery is necessary', rather than reassuring the patient, alerted her to the idea that her illness was more widespread than she had believed.

Another patient who was not having treatment and hence did not see her consultant in the relative privacy of the review clinic, was aware that the doctor never came close enough to have an intimate conversation.

"Dr. S always stands right over there so there's no chance of asking anything private. I don't think they want to let me in on what's going on."

Whether the patient would have asked anything had the opportunity been provided is open to speculation. The fact that the doctor physically distanced himself was meaningful to the patient who, at this time, was also asking nurses questions about the meaning of new symptoms. Nurses were aware of how their behaviour could at times 'give the show away'. Hesitancy in finding a suitable response, avoiding eye contact, blushing and on occasions having to control their own tears when patients expressed their feelings, could all constitute cues for alert patients.

The extent to which patients relied upon non-verbal cues was not established in the present study but the importance of informal cues from staff cannot be underestimated. It was not often that patients asked direct questions about diagnosis or prognosis. While the general lack of privacy and continual sense of business may have contributed to patients' inhibition, they did ask about other matters affecting their stay in hospital. But even in these matters, patients often did not ask staff, feeling that this would cause an imposition on extremely busy people. Not asking is therefore attributable to both a general reluctance to ask questions and to not being prepared for what they may have been told.

Rather than ask directly, they gradually built up a picture of their own condition which was acceptable to them at that time, by piecing together the information available through the informal network.

Reliance on informal information provided greater freedom to go at their own pace, be selective in what was abstracted and draw conclusions in accordance with the picture of their illness they were attempting to construct. Patients attempting to construct or maintain an optimistic outlook would avoid, ignore or suppress cues to the contrary, while seeking confirmation for their beliefs. Those seeking to reduce uncertainty by establishing the truth would be equally alert for cues to provide a realistic picture, but also to maintain hope.

Thus patients could rely exclusively on informal information to construct their prognosis. Not because information was necessarily totally denied in the formal network but because the informal network provided greater opportunities for selectivity by differential information seeking and avoidance. Rather than ask, with its attendant danger of being told too much, (patients were not to know they would not be told), they could exert their own control over what they chose to perceive or discount.

Some of those seeking the truth did ask, up to a point. But the answers given were not necessarily the version of the truth they sought. Patients did not challenge what they were told although they realised they may not have been told the whole story or may have been given a more reassuring version than was really the case. They realised what they were told may have been a well-meaning attempt to allay their anxieties or, alternatively, it may have been the truth. Not knowing how much reliance to place on what they were told, patients could supplement formally obtained information by informal cues. They did not discount what they were told but checked it out. Using both types of information they were able to substantiate or modify formally given information in their quest for the truth and follow up cues by asking about their meaning.

Informal information was generally more pliable than that formally obtained. It allowed for greater patient control over what was perceived and suppressed and the interpretation of cues in accordance with a particular conception. At different times and for different patients cues assumed relatively more or less importance. For instance, it was the usual practice for patients to go home for the weekend if they were well enough. Patients receiving radiotherapy to the throat however, as their treatment progressed, entered a period when the severity of tissue reaction warranted their continued stay in hospital. This restriction on leave and the severity of response was interpreted by two patients as indicating a more serious prognosis than they had initially believed. Another patient, however, interpreted precisely the same events as indicating that 'the treatment is really working. That means it's doing all that it's supposed to be doing' and so, increased her optimism.

This variability in the significance of cues and their interpretation was characteristic of patients in the process of constructing and maintaining particular interpretations of their illness. This was particularly so when patients attempted to maintain a hopeful outlook against the odds. That they were in hospital meant that they did not absolutely deny the illness, but they had constantly to seek cues indicating a hopeful outlook and attempt to suppress others. Patients had to modify their existing beliefs or construct beliefs that cancer need not be fatal and that their particular case would prove amenable to treatment. Others were concerned with establishing more precisely the severity of their illness.

Cues in the Environment

From the time patients entered hospital cues relating to prognosis were available to them. This was especially so concerning treatment, which was, after all, the *raison d'être* for most of them being there. Once admitted most patients were eager to begin treatment at once and many did. When delays were caused because tests or examinations had to be arranged or repeated or shells made for facial treatments some patients became worried in case there was a greater problem than had been anticipated.

"I know it's malignant but now I'm worried at this delay in case they've found out something else. I hope it's not turned into cancer now."

The same stream of events allowed patients to play down the potential seriousness. Delay could be interpreted as indicating their condition was less serious. Because of difficulty in arranging a particular test it was suggested to one patient that he go home again for a few days.

"It can't be as bad as I thought or they would be hurrying things up more than this."

Some patients had been told that their radiotherapy was 'purely precautionary' and not essential after surgery. Once they were faced with a series of tests some began to wonder whether, in fact, there was 'something left in' or whether the doctors were looking for further evidence of disease. The idea of tests as a basis for planning treatment was not always sufficient to allay suspicions. Once treatment actually began most patients were noticeably relieved. For many, radiotherapy was an unknown quantity and myths and apprehensions about what it actually entailed were rife. After treatment had begun the actual mechanics of treatment grew into perspective, patients were glad that something was actually being done. It meant that the

doctors had made up their minds and could begin their treatment.

The type of treatment regime presented clues about severity which were interpreted in the light of lay knowledge. Many patients had already had surgery prior to admission and the addition of radiotherapy could be interpreted as either a good or a bad sign. Good in that radiotherapy was just an added safeguard after successful surgical intervention, their condition was worth having the 'full works'; or bad, in that perhaps surgery had not been completely successful after all. On the other hand radiotherapy without surgery could be a bad sign.

"If they don't take off the breast and just give you the heat treatment that means it's too deep seated to be removed."

However, for other conditions, absence of surgery was a welcome indication.

"I was told it could mean an operation to remove the voice box or this treatment. I think if they can do the treatment by itself it's better. I was advised that way. They only do the operation if it's a last resort. I'm hoping it won't come to that."

Thus the significance of particular cues varied with the site of the malignancy and for different patients depending on how they were coping with their illness. It was notable that when two patients both with advanced metastatic breast cancer were in a four-bedded room and one was dying, the other, who was trying to attribute her current back problems to a cause other than cancer, could not tolerate sharing the room and asked to be moved away. The other patients in the room were less affected. On another occasion two patients with the same advanced cancer and one near to death preferred to stay together. The non-terminal patient knew her illness was very advanced and that she would die but the cues available did not hold the same threatening significance.

Cues were also attached to the number of radiotherapy fractions. Patients generally did not appreciate the differences attached to the low and mega voltage machines and were more concerned with the 'number of treatments' rather than the total rads given. The number of treatments was taken as a cue to the stage of the illness.

Two patients having a radical course to the throat in twenty-five fractions:

"If it had been caught earlier I might have got away with only five or even ten."

"I thought I would be getting twenty like the rest but now I'm told it's twenty-five. That can't be a very good omen."

Such an interpretation was not inevitable however. To receive what was regarded as a 'full course', i.e. the most common radical course of twenty fractions, indicated to some a more hopeful prognosis.

"I'm better off having it all. That means I'm well enough to take it. Some aren't so lucky."

For those having a first course which was only five treatments, i.e. a palliative course on a 250 kV machine, only to be having five could be interpreted as encouraging, especially if symptomatic relief was also experienced.

"There must be hope after all. My breathing's easier and I'm off treatment by tomorrow."

Those readmitted for further courses of treatment could equally interpret having only five sessions as a good sign.

"It can't be so bad. Last time I got twenty on a big machine. This time it's only five and not so strong."

Thus it was possible to place an optimistic interpretation on almost any form of radiotherapy treatment. For those readmitted however further radiotherapy was often interpreted as a sign of advancing disease. Patients having chemotherapy with or without radiotherapy could equally interpret this with optimism or pessimism.

Patients could scarcely avoid some cues impinging upon them. Their own physical progress, particularly response to treatment was a strong clue. Signs of improvement were sought - reduced swelling, normal functioning, less pain, were all hopeful signs of the effectiveness of treatment. Even when patients suffered side effects this was rationalised as necessary for the treatment to work, not to have had such unpleasant consequences would have indicated that the treatment had been less effective.

"I was relieved when the bool* came up in my throat. I was beginning to worry the treatment hadn't taken. Now I know it will be all right."

Some patients of course were more active than others in seeking cues in keeping with their adjustment strategy and to the level that they could cope. Some were at pains to avoid anything which may have shattered their tenuous hopes. As well as this being evident in the selective use made of cues, involvement in the patient communication network further exemplified the relevance of informal information.

The Patient Network

Other patients could play an important part not only as a source of information, but also as a means of coping with the stress of having cancer and being in hospital. Bloom et al^(1,2) have described how patients in psychiatric wards develop groups or cliques in response to particular needs.

Among cancer patients in the wards studied, it was evident that two types of sub-group existed. As McIntosh⁽³⁾ found, one type dealt

*Feeling experienced like a marble in the throat which had been described by others having the same treatment.

with needs for ordinary social contact and discussion of what was happening on a fairly superficial level. The second type of group existed solely for the purpose of discussing the illness. This does not mean that patients did not discuss illness related matters in the friendship groups. They did, but the level of discussion was superficial and limited to enquiries about the state of health and progress through treatment, and not unlike much of nurses communications with patients. Different factors were associated with which patients participated in particular groups.

Friendship groups evolved on the same basis as any friendship tie. In such a large ward not all patients encountered all others and associations were formed between compatible patients who happened to meet by virtue of their bed location, where they sat at meal times, who happened to have treatment at the same time, going to the sun lounge or television room. Friendship groups often formed within four-bedded rooms when immobile patients became involved, although patients from different rooms also established groups. Similarity of condition was not important in determining friendship group composition. By comparison, in the illness discussion groups there was usually a common condition or treatment uniting participants. The other criteria for participation was a willingness to discuss details of the illness.

Group boundaries were fluid and constantly changing as new patients were admitted and others discharged. Groups were usually small, comprising no more than four patients. Individual patients could belong to several friendship groups which met in different places as well as to different illness discussion groups for the purpose of discussing different aspects of their illness and treatment. A group of women of child bearing age, for instance, came together to

discuss the issues of further children and sterilization. This group did not exist for long however and the women were observed with others at different times as they attempted to understand the significance of the extent of surgery and the meaning associated with the side effects of treatment. Usually groups were of like sex, but occasionally patients of the opposite sex with the same diagnosis came together.

Although a greater measure of privacy was created for patients by having smaller rooms, Skipper's⁽⁴⁾ observation that this increased patients' dependency on formal channels of communication was not borne out. Patients who wanted to find out about themselves and who were mobile were able to do so and associate with other patients without restriction.

Often friendship and illness discussion groups overlapped, and, while illness discussion groups contained friendship elements, the converse was not the case. Some patients, while participating socially, had no wish to discuss their illness with others, and so did not become involved in discussion groups. This was for different reasons.

As already described, some patients did not want to learn about their illness. Had they joined in a discussion group they risked hearing about others' illnesses which also contained implications for themselves which they had no wish to hear. They made this clear to me when I asked them, as well as to other patients.

"I prefer not to talk about it and certainly not with the others. It's better to keep yourself to yourself in a place like this. Otherwise you hear all sorts of frightening things."

They did not want to hear about the plight of others. It would have been too depressing. Coping with their own problems was enough.

"You could get very upset if you were to dwell on it like some of them do. I think I've got enough in my own plate without any more."

Patients did discuss problems with others, but these were associated with work, home or family, and not directly related to their illness. They dare not jeopardise their current means of maintaining hope by engaging in discussion of their illness to any depth.

Only occasionally did patients become involved in listening to illness talk they would have preferred to avoid. This happened when for instance, a naïve patient spoke about her husband losing a leg due to cancer and then dying, with a patient who had, at that time, metastases in her femur. On another occasion some women talked about the effects of disseminated breast cancer and paralysis to a patient with advancing disease who had been prepared in the past to talk about having cancer but not about prognosis. This discussion went beyond the limits which she was prepared to hear and she was less inclined to participate again. Most often however patients were more sensitive to the wishes of others, avoiding talk in their presence and not contradicting their beliefs about their illness.

- P.a "Mrs. T. says she has a growth on her tongue. She told me it was caused by putting her false teeth in after they had been soaked in neat bleach."
- P.b "Yes, she told me that too. She was in a hurry to get the bus. She put them straight in her mouth."
- P.c "Well, I don't think the doctor would tell her that was the cause of it. She just thinks that."
- P.b "So long as she's happy believing it."

Patients who did not want to join in discussions were usually able to indicate this. The subject of their illness usually came up at some point and these patients had to show that they did not wish to go into details.

"Of course I've been asked about myself. It's the main subject with some of them. But I just say it's to do with the glands and talk about something else. After all it's not anybody's business and I don't want it broadcast."

"I try to be sociable but I'm not one for getting into a huddle. I make it plain I'm here to get better and that's all I'm interested in."

Patients who did not wish to participate were seen to withhold information about themselves, cut off conversation by changing the subject or busying themselves in newspapers or books, even ignoring the comments of others. A few patients persistently talked about their illness however. This was difficult for their fellow patients who did not wish to be drawn into such discussions and became upset by the repetitiveness of the subject.

"Miss D. goes on about it the whole time. Whenever anyone comes into the room she's up to see if they're going to tell her anything. She goes on about it, if it can be cured and what they can do. It's Mrs. G. I'm sorry for. She's stuck in bed all the time and she's worse off than any of us. At least we can go out. You don't like being rude to people but we've all agreed to try to ignore her. If we listen, it's like egging her on."

Patients also suggested to others that it could be harmful to dwell on their illness too much, "it doesn't do any good to get all wrapped up in it". They even went so far as to suggest that it was better not to find out, especially from other patients, because the 'horror stories' were not likely to be true anyway.

"You'll just get yourself and everybody else worked up if you listen to what they say."

Thus for their own good as well as that of persistent offenders, some patients attempted to decrease the amount of talk about the illness.

Some patients taking part in discussion groups were very much listeners and advice givers rather than seeking information about their own illness.

"I'm the psychologist in there. They all talk about their problems, about having their breast off and about the treatment and so forth. But who am I supposed to talk to?"

S.B. "Do you not talk to the others like they do to you?"

"Goodness no. I mean I feel I've had experience of life working in hospitals and I can be of some help. But I think really we should have professional advice. After all some of the things they say are way off beam. Like Mrs. J. was saying about her aunt dying of a brain storm after she had her breast off. Well you just go along with it. If I wanted the facts though I would ask my own doctor. I intend to do that once I'm home."

Others preferred to maintain their own counsel and did not participate at all, reserving any questions for medical staff.

"I prefer not to talk about it with anyone. The doctors have all the details and if I wanted to know I could ask them. Otherwise it's a load of old wives tales."

While some patients did not discuss their illness and avoided listening to others, nevertheless they were aware of the other patients' diagnoses. Even though patients themselves tried to avoid realisation, they knew other patients had cancer, like the patient who avoided washing the dishes lest she caught something. Remarkably patients were able to maintain their defences against realisation in the face of such knowledge. But they avoided becoming too entangled in discussing the details, being at pains to maintain the belief that they were different.

Within groups which discussed cancer, the nature of the illness was not always explicit. Sometimes this did happen when patients were trying to establish what other patients knew and their reactions. At their first meeting soon after admission while alone in the waiting room for treatment two patients launched into a discussion of their illness.

P.d "I see you've had a breast off too."

P.e "Yes, about three weeks ago."

P.d "It was only last week I knew mine was definitely malignant. I knew I was to come here but every time I asked somebody they changed the subject. I went to see my own doctor. He told me it was malignant."

P.e "I was warned. I knew when they took it off that's what it was. Anything suspicious at all and it's removed. Mind they got it right away. I was in within forty-eight hours."

Another group of three patients who were never heard to broach the subject before referred to an item in the newspaper.

P.f "I'm glad they've started to be open about this sort of thing. I think it's by far the best way."

P.g "Yes, cancer today is like what T.B. used to be. It was something you didn't like in your family. But that kind of thing is past now and it's getting the same with cancer. I'm not ashamed to admit I've got it. It's not catching or anything."

P.h "Yes, now that there is this attitude it's as if every second woman has a breast off."

While this degree of explicitness sometimes emerged, patients were more likely to retain euphemistic labels or refer to inexplicit diagnoses. This did not curtail communication and challenges the finding of Glaser and Strauss⁽⁵⁾ that in a cancer hospital few patients openly talked about anyone's condition. As Roth found with T.B. patients,⁽⁶⁾ Fox⁽⁷⁾ with metabolic patients and McIntosh⁽⁸⁾ with cancer patients, the illness was regularly discussed in great detail.

Avoiding the use of cancer or malignancy did not curtail communication. Those who knew were able to talk meaningfully while not alarming those who may overhear. Thus patients could enter into discussion groups without being absolutely aware that cancer was being discussed and could disengage should talk go beyond a level they were prepared to hear. The majority of patients who took part in discussion groups however were prepared to join in to the full.

Discussions often began after one of the group returned from review clinic. In friendship groups the significance of these sessions was marked by reporting back what had taken place, but in general terms,

"He's very pleased with how I'm doing."

"Everything going according to plan. I'll be finished on Tuesday."

Those more intent on exploring the finer details discussed more fully and raised questions as they tried to make sense out of events - Why did different illnesses receive different treatments? Could radiotherapy be repeated if it did not prove fully effective? How were the good parts not harmed if the nasty cells were killed off? Why were X-rays sometimes taken at the end of treatment and sometimes not? Why did some people not have to report back again?

There were always ways that patients could provide answers and explanations which reassured and encouraged their fellows - that radiotherapy was a precaution, that surgery was better done to remove the nasty bits, that side effects were worth enduring to achieve a cure, that tests were just to make sure everything was all right. Patients in discussion groups were able to help each other by favourably comparing themselves with those who were more ill, or by vying with each other as to whose condition was worse.

"We haven't much to complain about when you look round and see some of the poor souls in here. Really we should think ourselves lucky."

"I was in the Vic with Mr. F. But his was one of the open and shut cases. They couldn't do anything for him there. My operation was a success and the radiotherapy was only suggested as a safeguard."

P.i "There weren't any symptoms or anything, but I had a smear test and it was positive. That's why I was sent in. They didn't do any operations, just like a D and C. Do you think that means they couldn't operate?"

P.j "No, I don't think that's it at all. I had a smear test too and mine was negative but I bled for two years then I had the operation and there were abscesses on both ovaries. They were both removed and the womb as well in case it spread to there. I don't think it's the results of the smear test so much as if you've had symptoms. I was sent after I changed my doctor. Mine must have gone on for two years at least. You didn't even have any symptoms."

They were able to encourage each other by talking about patients who had had cancer and were still well or patients who had died of entirely different causes. Patients encouraged others to be positive about their illness. One described how she had had a lung removed eight years previously for cancer and had kept well. Now she said she was in hospital with something entirely different. To me she said later "I didn't tell them it was cancer again though."

Patients who had had to adjust to mastectomy and were in hospital again described to others how they had felt, how husbands had reacted and how they had come to terms with their disfigurement. More practical issues of where to obtain prostheses and which were best were also discussed. Details of the course of the illness were also in evidence however, symptoms, further surgery, more radiotherapy, but patients stressed to others that no two illnesses ran the same course. Thus, patients who were readmitted were an important source of information. They had gone through it all before and knew what to expect. They could be too potent a source however, and to be subsequently avoided.

"I'm not going round to see Miss P. again. She's had all that I've had and more and now she's losing her sight. I don't know how she stays so cheery. But the others didn't do me any favours taking me round there."

In general, however, patients, in their behaviour to each other, reinforced the adjustment strategies they had adopted. Patients who sought information and mutuality with others were able to do so in patient groups. While the information they received tended to be reassuring, as in their communication with staff, patients were able to place their own interpretations on what was said. The mutuality through which they were able to share their worries also assisted in mitigating some of the stress. For some however seeking information in the patient network rather than assisting them to cope, simply

reinforced their questioning. Apparently they were not seeking answers to questions about their illness but to the question "Why should it be me?". In some instances patients seeking mutuality rather than deriving help, only alienated their fellow patients. Instances were rare however when patients upset the status quo by querying the effectiveness of treatment or the inevitable progress of the disease. Rather, patients' communication was characterised by sensitivity to the needs of others, reassurance and focussing on the good.

Friends and Relatives

The remaining source of informal information to patients in hospital were friends and relatives. It was decided that, in fairness to patients, they would not be observed while they had visitors. The data reported here derived from conversations with patients and their families and from interviews reported in Chapter 17.

Findings suggest that relatives intentionally communicated very little which was not intended to be reassuring. Indeed a mutual protection campaign sometimes evolved with the patient trying to protect the family, or at least some members of the family, and vice versa.

P. "I tell one of my sisters everything but the other just couldn't take it so as far as she's concerned I just talk about having back trouble."

Wife: "John told me what he had was slightly malignant. I think he was trying to protect me from the truth."

Patients did ask their relatives if it was cancer but in every instance known this was denied by the relative and some went to great lengths to provide alternative explanations.

Husband: "When I had been to the doctor she asked me what she had said. 'Oh' I said, 'it's one of those cysts and they have growths on them, roots and so on. They follow up the roots with the deep heat so they could kill it. The roots are there but you don't have to cut them up to there. You had these cysts and the roots grow out at different places'. So she accepted that. I said too about not carrying pails of coal and

things in general. But she pressed me and said that the treatment was for cancer but I said 'No. It had a sealing effect to seal off the roots otherwise they could cut and cut and cut and still find roots and keep going till the whole thing was cut away.'

This conversation happened on weekend leave, however, rather than when the patient was in hospital. Relatives in the main reflected the same sentiment as Oken⁽⁹⁾ found among doctors - that they thought it right that they had been told, they could take it but the patient should not be informed. If patients suggested their diagnosis then they were likely to be told they were 'talking rubbish' and 'that's just stupid talk', 'the doctor would have told if it was', 'they were too fat and healthy to have cancer'. The same beliefs were expressed as those held by staff - that patients would 'give up', 'lose all fight' and 'lose interest in life' should the diagnosis or prognosis be revealed. Even persistent questions did not break this resolve not to tell and so a vicious circle developed.

Wife: "He keeps on asking me. He was told it was only a small tumour and everything would be all right. He keeps asking me questions about what's going to happen to him and what's the matter. I put him off, or try to, but I think he would like to know. He keeps asking questions. I said ask the doctors, they could explain more. He said he did ask but they keep putting him off all the time. He doesn't seem to trust anybody now."

S.B. "He certainly seems to want to establish what his prospects are from all the questions. Why do you think you don't tell him what you know?"

Wife: "I think he would worry all the time about it. They told me two years. I think he would just worry if he knew that or what really was behind the tumour. But he's worried now. And you know why? Because I won't tell him and he imagines the worst."

In an attempt to reduce the likelihood of patients asking questions, some wives never visited without taking someone else along. Some relatives did not tell others for fear they would let something slip. Letters were written asking doctors not to tell. Any information which was passed on was couched in terms avoiding the real nature of the illness and its severity.

Parent: "We always just refer to his bad leg and when he will be able to get around again."

Daughter: "My father suspects what it is. He asked after a T.V. programme. But we just said it couldn't be because there was no history of it in the family and he was very fit for his age."

Such denial was not always the case and some couples had reached an understanding where both knew the diagnosis. It was not relatives who actually told the patient however, but some eventually came to reveal their knowledge to each other. When it was apparent that patients knew their diagnosis, then the family attempted to portray an optimistic prognosis by passing on favourable information they had received.

Husband: "After I had seen Dr. M. and he told me they thought there was a good chance I told Mrs. D. what he said. After all, that was more encouraging news than I had dared hope for."

Such information was volunteered to pre-empt questions after it was known that the relative had gone to see the doctor.

Most relatives had no doubt that they were doing what was best for the patient. A few however doubted their original action of denying cancer so forcefully. At this time however they were not prepared to change the situation but considered it could be in the patient's interest to do so. This view was typically associated with relatives themselves coming to believe that cancer was not inevitably fatal. Unfortunately, while the patient may have come to learn the diagnosis anyway, there was no certainty about how they would react to openness in the family.

Non-verbal cues that relatives were concerned were certainly emitted and perceived by patients. One patient told her husband not to be so anxious, it was she who had the cancer and not him and she was sure she would get well again. Some relatives were guilty that deceit had crept into their relationship but, "if he's going to die

I certainly don't want him to know anything about it. I only hope I don't give the show away."

Relatives then were just as concerned as others to engender hope among patients by denying that it could be cancer and providing any optimistic information they chanced upon themselves regarding the outcome.

While patients were in hospital those who earnestly sought to learn about their illness had no real need to seek such information from their relatives. There were plenty of opportunities elsewhere. Those wishing to construct a belief that it was not cancer or that it had been eradicated were more likely to make use of family members however since such views were assiduously engineered.

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CHAPTER 15

RELATIVES - THE STAFFS' PERSPECTIVE

In this and the following two chapters communication with patients' families is examined from the perspectives of both hospital staff and relatives. Data were derived from interviews and informal conversation with nurses and doctors and from observation of a small number of interactions between relatives and the house officer or nurses. Questionnaires completed by relatives as well as interviews with them provided information about awareness and desire for information, contact with staff and their reactions to the patients' illness. Relatives generally saw consultants off the ward by appointment and no such meetings were directly observed. Some of the comments by doctors were obtained at a staff seminar. On this occasion some of the data presented in the next chapter were discussed, providing an opportunity to raise some points regarding practices of informing relatives. No nurses were present on this occasion.

Doctors and Relatives

There was general agreement among medical staff that some member of the patient's family should be informed about the illness. They should be given more of the truth than was revealed to patients though they would be unlikely to be given all the details and this is consistent with the findings of other studies.⁽¹⁻³⁾ McIntosh⁽⁴⁾ found, as in the present study, that there was no routine to ensure that relatives knew as a matter of course. The onus was on relatives to seek out staff and, as a result, many saw none. The rationale underlying this method of working was that relatives wanting information would themselves arrange to see a member of staff and the machinery

existed by which to do so. In the present study the illness had been diagnosed elsewhere and it was supposed that most relatives would have been informed prior to the patient's admission to Radiotherapy. In most cases doctors believed there was no need for further communication since the patient's condition was unlikely to have changed much since admission.

Dr. P. "I've never found relatives reticent in asking to see me if they really want to know. Those who do will make it their business to ask. Of course most will have seen somebody about it already. After all they've all been diagnosed someplace else and they've all got G.P.s."

Some relatives were observed to be sought out by a doctor but this occurred only when the prognosis was obviously bad, when arrangements were being made to transfer the patient to an establishment for the terminally ill or when some special arrangement existed between the radiologist and a consultant from another department. If a patient's condition deteriorated quickly and it was obvious that they would die in hospital, relatives who were apparently unaware were likely to be informed of the fact. Otherwise it was up to relatives to find out about the patient and when they did they were likely to be given fuller and more factual information by senior doctors than were patients.

The house officer did not usually see relatives except when the patient was terminal or some special reason prohibited them from making an arrangement to see a more senior doctor. Occasionally however if a relative happened to ask a nurse to see a doctor, and the house officer was available, he could be involved. They did not relish this aspect of their work, partly because they felt that they did not know enough about the patient to be able to offer a reasonably ^e account of the position:

Dr. K. "I think it's the consultant's job to see relatives here even if it means coming in in the evening if they have to. After all that's what they're paid for. It's not easy when you don't get the case notes up here. We can tell them roughly what's in it for the patient but they're better to see the consultant if they really want the details. I sometimes see a relative here if I'm nabbed but I don't go out of my way."

Telling relatives was one of the unpleasant aspects of the job.

But why should relatives be privy to information which was denied to patients? A number of reasons were given. These included the belief that someone in the patient's family should be informed because they had a right to the information. Those relatives who were informed, were considered more likely to act in a reasonable manner because they could understand why the patient was not getting better and not keep badgering the staff with questions. Being informed also contained implications for managing patients. If relatives understood they could prepare to care for patients through the course of the illness as well as prepare for the eventual outcome should it prove fatal.

Other reasons have been advanced to account for doctors' practices of being more truthful with relatives. Parkes⁽⁵⁾ considers that since relatives will probably find out eventually from some other source, if they are not informed by the doctor in charge, then they may lay charges of being misled. McIntosh⁽⁶⁾ advances the same argument, that the doctor exercises less control over the relatives information network than that of the patient and given the widespread belief that relatives should be told, then they are more likely to learn elsewhere. By informing relatives of the truth, this should reduce the dangers of relatives receiving contradictory information and thus precipitating a clash and loss of confidence.

McIntosh⁽⁷⁾ also suggests that should the patient suddenly deteriorate and the relatives have not been informed then they may

level accusations of incompetence or negligence against the doctor. One doctor in the study felt that given the nature of the illness and probable untimely death then it was not unlikely that relatives would vent their anger against medical staff anyway. Keeping relatives informed, while not necessarily circumventing this reaction, could provide the basis for a better relationship.

Of course a policy of informing relatives who asked while not disclosing to patients was not without its risks and there were several potential risks. One was that relatives, even though they asked, may not be able to take the news. Consultants had little opportunity to become acquainted with or assess relatives prior to an appointment. Doctors believed that when relatives went to the effort of asking, it indicated that they really wanted to know the facts. Instances were recalled of relatives having been informed of bad news when they had not sought it out. That they later denied being told was attributed to being given information that they were unable to withstand. This reinforced the belief that only relatives who asked should be informed. Even then however, they need not assimilate all of the information. However the belief that those who asked genuinely wanted to know resulted in only two relatives being known to have information withheld during the course of the study because they were assessed as emotionally unstable.

There was always the possibility too that while relatives may not intentionally disclose to the patient, they could emit cues should they be upset.⁽⁸⁾ To avoid immediate encounters between relatives and patients, interviews were always held in the privacy of the doctor's office and, by having appointments at strategic times, the patient need never know that the interviews had taken place. In only one instance was a patient observed to make an appointment for his wife to

see the doctor and only once was a patient and her husband known to be interviewed together. Both were already aware of the diagnosis prior to interview.

In most instances however, relatives were believed to avoid passing on information to patients and so while some risk attended disclosure it was unlikely to precipitate the patient's awareness. By virtue of the stage in the patient's illness, had they wished, relatives would have had the opportunity to disclose at least the diagnosis. Like staff, however, relatives were more likely to seek to protect the patient and so doctors risked comparatively little in following their policy of disclosing information (with the exception of the terminally ill) only to those who sought it.

Nurses

Like doctors, nurses thought that someone in the patient's family should know the truth about the illness, or at least as far as this was possible. While telling was the doctor's responsibility, it was of trained nursing staff that relatives usually made their first enquiries. Unlike contacts with doctors which were rarely without an appointment, relatives simply asked the nurse at the nurses' station or the first one they happened to encounter in the corridor. Most often questions were of an indirect nature, "What's this treatment for?", "Can you tell me about my father", and, rather than disclose details of the illness, nurses advised relatives to see the patient's consultant.

"I think you should have a word with Dr. G. about it.
He will be able to tell you more than I'm able to."

Relatives were then told about making an appointment through the general office.

Not all relatives felt able to come to the hospital during the day especially to see a consultant and so some persisted with their questions to nurses.

On a Sunday:

"I can't get over here in the day time. I've a job to do. Surely you can give me some idea of what's wrong with her and what's happening?"

Nurses however resolutely refused to disclose anything beyond general comments about the patient's current state of health.

S/N "I'm sorry but I'm not allowed to say and in fact we don't have all the details in the ward. Maybe you could telephone even if you can't come yourself? Your mother is standing up to the treatment very well considering her age."

While more experienced nurses also routinely referred relatives to the consultant, some said that rarely, in response to direct questions about whether the illness was cancer, they had agreed that it was.

They would never indicate a prognosis however.

S/N "Yes, I've told a relative it's cancer, or at least agreed when I've been asked if it is. There's no point in brushing them off if they put it that way but I don't feel qualified to go into the details. I always advise them to have a word with the consultant. They're generally very good at seeing the relatives here so long as they make an appointment."

Only once during the study was a nurse actually observed to disclose a diagnosis to a relative and then it was in a telephone conversation. A son asked whether it was cancer and the staff nurse agreed that it was.

Most often however nurses' replies to questions about the patient were confined to the patient's current state and to treatment. This was facilitated by the general form of most of the questions:

"I was wondering about my mother."

"Can you tell me about Mrs. G?"

They could be answered without reference to the underlying illness.

"Treatment is progressing very well and we're pleased with how he's doing."

"These symptoms are just what we would expect just now. It's due to irritations caused by the treatment. It will settle down again after the treatment's finished."

Relatives were also given stock replies when the patient was declining.

"Well if it's obvious there's no point in trying to hide it. If they're really terminal I just say they're getting weaker or they're deteriorating. The relatives are usually in the picture anyway by this time but it's better not to be too explicit. If they're near the end you can let on they're sinking but you can't always tell. Take Miss P., she's been at death's door and the next thing she's up again so you can't be sure that this is it. We're not supposed to say too much anyway, just kind of keep them in the picture."

Consistent with what they said about communicating with patients, nurses said that they would be helped in their response to relatives by knowing what the doctor had told them. But they knew that doctors were likely to be much more forthcoming with relatives than they were with patients. While nurses did not ask relatives what they knew, occasionally a relative would inform the nurse.

"I was told at the City he had a tumour. What I'm wondering about now is why his breathing is getting worse."

On rare occasions too a relative persisted in attempting to engage nurses in conversation and nurses found such encounters difficult to manage.

S/N "She's been here three days in a row and I don't know what she expects me to tell her. It's as if she knows and she's hoping for some miracle that it will just disappear. I don't know what to say to her now apart from there's no change. There's nothing to tell her."

Such frequent contact were exceptional however, most relatives having little contact with nurses apart from the families of terminal patients and of those who had been readmitted to the ward on several occasions.

Student nurses saw little of relatives and it was the trained staff who dealt with their questions. Unlike the consultants who saw them in private however, the only time that nurses were observed to be with relatives in the privacy of the duty room was after a bereavement.

Meetings tended to be of a more casual nature, the relative approaching the nurse either in the corridor or at the nurses' station, also adjacent and open to the main corridor.

On the whole nurses played a small part with relatives and, as far as information about the illness was concerned, their comments were limited to the patient's immediate condition.

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CHAPTER 16

A QUANTITATIVE ANALYSIS OF CONTACTS BETWEEN RELATIVES AND HOSPITAL STAFF

A self administered questionnaire was used to ascertain the frequency of contact between relatives and hospital staff. The overall aim of the questionnaire was expressed as collecting information about facilities for visitors to the Department but embedded within this were questions about contact with staff, communication and relatives' satisfaction. The broader framework was used to make the questionnaire acceptable to patients, some of whom scanned the blank copies, and to staff. Both nursing and medical staff examined and commented on the questionnaire prior to it being piloted. Some changes were introduced on the basis of their comments, primarily in shortening the instrument. A pilot exercise was carried out with twelve relatives, the first six of whom discussed the questionnaire after completing it. Some minor adjustments to wording were made. The questionnaire is reproduced in full at Appendix V but only data related to contacts with staff are reported here.

The Sample

The samples for the questionnaire study as well as the interview study (to be discussed next) were obtained from next of kin of patients discharged during a ten week period from March to May 1974. Excluded from consideration were patients in hospital for less than five days and patients discharged for terminal care to another establishment. Otherwise no selection was made on the basis of patient factors. Of a total of 303 patients discharged from both wards, 129 (42.6 per cent) were lost from the sample. This was due primarily to being unable to ascertain their expected date of

discharge in advance from the nursing Kardex and to such infrequent visiting by next of kin that it was not possible to contact them toward the end of the patient's stay. Other reasons included next of kin too young to co-operate, the patient showing reluctance for the relatives to be approached, and on two occasions a doctor requesting that a questionnaire should not be given because relatives were upset by bad news. Relatives of patients readmitted and discharged during the ten week period were not asked to complete a second questionnaire.

The representativeness of the sample obtained in terms of medical condition or social characteristics was not ascertained. Table XXV suggests that relatives of longer stay patients, that is patients in hospital for two weeks or longer, are over represented.

TABLE XXV

LENGTH OF STAY OF PATIENTS INCLUDED IN QUESTIONNAIRE SAMPLE COMPARED WITH THOSE OMITTED FROM THE SAMPLE

| Length of patient stay at time of discharge | Number in questionnaire sample | | Omitted from sample | | Total | |
|---|--------------------------------|------|---------------------|------|-------|------|
| | | % | | % | | % |
| Less than 1 week | 16 | 11.4 | 35 | 27.1 | 51 | 16.8 |
| 1 week but less than 2 weeks | 31 | 22.2 | 35 | 27.1 | 66 | 21.8 |
| 2 weeks but less than 3 weeks | 28 | 20.0 | 9 | 7.0 | 37 | 12.2 |
| 3 weeks and longer | 65 | 46.4 | 50 | 38.8 | 149 | 49.2 |
| | 140 | | 129 | | 303 | |

Kolmogorov-Smirnov 2 sample one tailed test

$$\chi^2 = 10.74, \text{ d.f.} = 2 \quad p < .01$$

Method

An approach was first made to patients one week to three days before their expected discharge date and permission sought to approach their next of kin. After permission was gained and visiting arrangements determined, relatives were contacted at or as near to the time of discharge as practicable. Of the 140 questionnaires distributed 111 were returned of which three proved too incomplete to be used. The remaining 108 questionnaires represent a 77 per cent response rate. Non-response was due primarily to instances when the relative failed to appear at the expected time and the questionnaire was left for the patient to pass on, and when the relative took the questionnaire to complete at home. Twenty (70 per cent) of the non-returned questionnaires were in these categories. In another three instances it was known that the patient had died unexpectedly shortly after the questionnaire had been given. Questionnaires given to complete at home were placed in a stamped, addressed envelope while others were collected personally or deposited in a sealed envelope in a box at the nurses' stations in the wards.

Findings

The 108 questionnaires were returned from 97 (90 per cent) next of kin and 11 (10 per cent) other relatives or friends. The inclusion of other than next of kin was due to the latter residing too far away to be able to visit or being too infirm to complete the questionnaire. The next of kin in such instances would seem unlikely to have had contact with hospital staff and so it was considered justifiable for some other close family member to provide the data. When friends were indicated as next of kin this was the patients' definition.

Relationships to the patient included

63 spouses
28 children
7 siblings
5 nieces, nephews or cousins
3 parents
2 friends.

Contact With Doctors

Relatives were asked whether they had already spoken with a doctor from Radiotherapy, either in the Department or at an out-patient clinic. Of 106 relatives answering the question 34 (32.1%) responded that they had already done so and the remaining 76 (67.9%) reported not having spoken with a doctor. A further two relatives reported that they intended to see the doctor prior to the patient's discharge. That only about a third of relatives had spoken with a doctor in Radiotherapy could have been due to information having been obtained about the patient either from the General Practitioner or from one of the doctors who were involved at the time of diagnosis or primary treatment elsewhere. In such circumstances relatives may have felt that they had no desire for further contact with medical staff at this time. Alternatively some other member of the patient's family may have discussed matters with medical staff, the next of kin being unable, disinclined or unwilling to do so. In order to ascertain the extent to which these conditions prevailed, questions were asked about contacts with other doctors and by other family members. Ten relatives had failed to supply complete information on the three questions asked due to not knowing whether any other family member had spoken with a doctor. Full data were obtained therefore from 98 relatives.

Of the 30 who had spoken with
a doctor in Radiotherapy

4 relatives (13.3 per cent) had
spoken with another doctor and
so had another relative

18 relatives (60.0 per cent) had
spoken with another doctor but
no other relative was known to
have done so

8 relatives (26.7 per cent) had
not spoken with another doctor
nor was another relative known
to have done so.

Of the 68 relatives who had
not spoken with a doctor in
Radiotherapy

8 relatives (11.8 per cent) had
spoken with another doctor and
so had another relative

22 relatives (32.4 per cent) had
spoken with another doctor but no
other relative was known to have
done so

9 relatives (13.2 per cent) had
not spoken with another doctor
but another relative was known
to have done so

29 relatives (42.6 per cent) had
not spoken with another doctor
and no other relative was known
to have done so.

These data indicate that 52 of 98 (53.1 per cent) of next of kin had
some contact with ~~Radiotherapy doctors~~ ^{DOCTORS OUT WITH THE RADIO THERAPY SERVICE} compared with 46 (46.9 per
cent) who had not. Combining next of kin and other relatives, in

61 instances (62.2 per cent) some relative had discussed the patient elsewhere. For only eight next of kin were medical staff in Radiotherapy the primary source of information and so, when doctors said that relatives were likely to have been informed elsewhere, this was quite true for the relatives they happened to interview. Among those who did not see a doctor in Radiotherapy, however, one third also had had no contact elsewhere and the patient was discharged with the relative still not having talked with a doctor. These data refer only to contact with doctors, not what they had been told about the patient's condition. That so many relatives had no contact with doctors goes some way towards refuting Lamerton's⁽¹⁾ assumption that the relatives of cancer patients are nearly always told, at least at this stage of the illness.

It must also be borne in mind that relatives were excluded who had difficulties in visiting the hospital regularly. They tended to visit when there were no doctors available. Had this group been included then the figure for no medical contact would almost certainly have been higher since about one quarter of relatives who saw a doctor in Radiotherapy also had had no medical contacts elsewhere. While the majority of relatives had no contact with medical staff in Radiotherapy, a few had had more than one interview. It was ascertained that 27 relatives had encountered a doctor once, four relatives had seen one twice and three on three occasions or more. This substantiates Parkes⁽²⁾ view that the norm for imparting information to relatives is a single interview with a strange doctor.

Not all relatives however may wish information from doctors and the question was asked "Since the patient has been in the Department, have you felt at any time that you would like to talk with a doctor about the patient?" Of the 72 relatives who had not spoken with a doctor in Radiotherapy, 26 (36.1 per cent) said they

had no desire to do so while 46 (63.9 per cent) said they would have welcomed the opportunity. Why did this group not use the facilities available? Answers to the question "Are there any comments you would like to make about facilities in the department for seeing medical staff?" indicated that fifteen relatives reported perceived difficulties in making contact. Comments included:

"The ward seems remote from medical staff and going to see one somehow seems making a fuss."

Others were unaware that an appointment system existed and suggested one be set up.

"How would it do to see someone on the medical staff by appointment?"

Others knew of the system but some aspect posed difficulties.

"There are no facilities for seeing a doctor at evening visiting times, which in my case would be an advantage; otherwise it would mean losing a whole day's wages."

The theme of the desire for privacy was apparent in several comments, for example

"Some facility for discussing the patient's treatment in absolute privacy."

Consultants did see relatives in private and these comments are probably a reflection of lack of this knowledge or of a desire for contact in privacy with other grades of medical and nursing staff on the ward.

Relatives who did communicate with doctors were predominantly responsible for initiating the contact. Arrangements to see a doctor were made in the following ways:

| | |
|--|-----------------|
| A nurse made the arrangement | 14 |
| Wrote or telephoned office/doctor | 13 |
| Self initiated in ward | 9 |
| Patient made arrangement | 1 |
| Arranged to see a doctor at out-patient clinic | 1 |
| Doctor asked to see relative | $\frac{1}{39*}$ |

(*This totals more than the number of relatives who saw a doctor since different arrangements were used by those who saw on more than one occasion.)

The onus was certainly on relatives to contact the doctor and those who did so found arrangements satisfactory:

"existing facilities very good"

"no real problem in seeing medical staff. If not available then telephoned again and made an appointment."

Others found taking this initiative more difficult:

"Consultation with qualified medical staff is difficult at any time. Someone available in a private office on the ward floor would be an advantage."

"I would like to discuss my husband's future care but I find it difficult to make the approach and no one seems interested in approaching you."

While it may be argued that relatives who had a desire for contact with medical staff would manage to achieve this, the constraints imposed by the circumstances in the ward may have been enough to tip the balance against carrying out the intended and desired action. Apparently the perceived absence and unapproachability of medical staff and perceived lack of privacy interfered with the wish to discuss the patient's illness. While such situational constraints to action existed for some, for others, avoiding talking with medical staff permitted the relative to maintain hope. One wife wrote

"If you don't know something you don't worry."

while another commented

"I would like to see a doctor but I'm afraid of what he might tell me. I know what this treatment is for and I don't want to know any more."

A relative also expressed the belief that

"there is no need to see a doctor. If it is serious then the doctor will ask to see relatives. It would be wasting their time as they are very busy people."

In this respect, some relatives showed the same adaptive behaviour as patients, preferring to remain in a state of uncertainty rather than risk hopes being dashed by what doctors might tell them.

What did doctors tell relatives? In such an impersonal and relatively public data collection instrument it was not feasible to go into details. Broad headings therefore were provided and relatives asked "When you saw the doctor(s) did you discuss:-

the patient's current illness:

the treatment the patient is having;

the length of stay in hospital;

how to look after the patient at home.

If you discussed other things, can you say what these were, please?"

Only three relatives chose to elaborate and so, unfortunately this question revealed little of the details of what transpired between relatives and doctors.

Table XXV I indicates that almost all of the relatives who saw a doctor discussed the patient's illness but only six (18.2 per cent) discussed the patient's after care and 22 (66.7 per cent) the patient's treatment. Taken as a proportion of the total sample providing the information 20.8 per cent discussed treatment and 5.7 per cent discussed after care. While it has been argued that some relatives may not have wished to discuss the details of the patient's illness at this time either because they already knew or had no desire to know, it came as a surprise that so few should discuss the nature of the patient's treatment and after care. This is especially so in the light of a substantial proportion of patients suffering unpleasant side effects of treatment or who were otherwise incapacitated. As will be seen, nurses did not take on this responsibility.

TABLE XXVITOPICS DISCUSSED BETWEEN DOCTORS AND RELATIVES

| Topic | Number of relatives N = 33 | Percentage of 33 who spoke with a doctor | Percentage of 106 who provided information |
|--|----------------------------------|---|---|
| Current illness | 31 | 93.9 | 29.2 |
| Treatment | 22 | 66.7 | 20.8 |
| Expected length of stay in hospital | 10 | 30.3 | 9.4 |
| Care at home after discharge | 6 | 18.2 | 5.7 |
| Others (transfer to another hospital, help at home, history of illness and future, management of state of mind) | 3 | 9.1 | 2.8 |

That so few relatives discussed length of stay is less surprising since most patients had ascertained the duration of treatment at the beginning and were likely to be discharged almost immediately on its completion.

An attempt was made to assess relatives' satisfaction with information from medical staff. They were asked whether they felt they had been given enough information, whether things had been fully explained and whether they had understood what was said. Of the 34 relatives who had spoken with a doctor in Radiotherapy, 30 answered. Twenty-three relatives felt that they had been given enough information and that matters had been fully explained while seven thought they had not been given a full explanation. Five of the thirty also said that they had not fully understood what was said to them. While

most relatives reported being satisfied, one third said that they would have liked more information about specific topics or at different times. They wrote:

"Why is treatment necessary?"

"A clearer explanation of the condition and the side effects of treatment and how to help the patient more at home."

Some wanted more information about the future:

"What has been done to my husband, what are they doing now and what kind of future do we have?"

"My sister's future treatment."

"How long the patient will live. I feel left hanging."

One relative felt that he had received the information too late:

"Would have preferred to know at the beginning instead of at this late stage. I feel I was misled."

Some other relatives who had not seen medical staff noted in other parts of the questionnaire that they would have liked to know what response patients were having to treatment:

"Is this treatment doing any good?"

"Whether my mother is going to benefit from going through all this."

Some however indicated that what they wanted was:

"reassurance about the patient and the treatment."

"I feel not one bit reassured each visit. Certainly I knew what to expect from my own doctor but I think to be sought by a doctor or a sister would be more personal, not like an animal in a cage. Certainly I know it's such a big hospital with many patients but I think a word of comfort would bring more comfort to patient and relative alike."

Not unnaturally relatives wanted to be reassured about the treatment and its outcome. Without enquiring however, this did not happen and to have enquired risked being given information contrary to the reassurance they desired.

Contact With Nurses

Relatives were asked "Have you talked with any of the ward nurses about the patient?" Of 107 relatives providing information, only 27 (25.2 per cent) had spoken with some member of the nursing staff while 80 (74.8 per cent) had not done so. In terms of frequency of contact 9 relatives contacted nurses on each of one, two or three and more occasions. It was with trained nurses that relatives had spoken most often:

| | | |
|---|----|-----------|
| Staff nurse only | 13 | relatives |
| Ward Sister and Staff Nurse | 8 | " |
| Ward Sister only | 3 | " |
| Ward Sister, Staff Nurse and Student nurse | 1 | " |
| Ward Sister, Staff Nurse and nursing auxiliary | 1 | " |
| Student Nurse | 1 | " |

The greater frequency of contacts with staff nurses reflects their larger numbers as well as the increased likelihood of a staff nurse rather than a Sister being on duty in the evening when relatives visited. Trained staff are likely to have more information about the patient.

Relatives were asked to indicate which of the topics noted in Table XXV//they had discussed with nurses. The most frequently mentioned topic was the patient's progress which substantiates what was observed of the nature of conversations between nurses and relatives. It is interesting to note that among relatives who spoke with a nurse, two thirds reported discussing the illness itself, but unfortunately the nature of this discussion was not ascertained. Again it is evident that the care of patients on discharge features

little in conversation with staff, less than 4 per cent of relatives discussing this matter. Only two relatives made comments indicating topics which did not fit into the categories provided.

TABLE XXVII

TOPICS DISCUSSED BETWEEN NURSES AND RELATIVES

| Topics | Number of relatives N = 27 | Percentage of 27 relatives who spoke with a nurse | Percentage of 107 relatives who provided information |
|--|----------------------------------|---|--|
| Patient's current illness | 18 | 66.7 | 16.8 |
| Patient's progress | 21 | 77.8 | 19.6 |
| Treatment | 14 | 51.8 | 13.1 |
| Length of stay | 11 | 40.7 | 10.3 |
| Discharge Arrangements | 10 | 37.0 | 9.3 |
| Care at home | 4 | 14.8 | 3.7 |
| Weekends at home | 2 | 7.4 | 1.9 |
| Others (results of tests, whether patient could bathe) | 2 | 7.4 | 1.9 |

Relatives were asked whether in their contacts with nurses they had been given enough information or whether they would have preferred a fuller discussion. Responses were almost equally divided, 14 of the 27 saying that they had sufficient information and 13 indicating that they would have preferred more. Consistent with the findings for medical staff, a fair proportion of those relatives who sought information would have welcomed a fuller discussion. All but one of the relatives who spoke with a nurse had initiated the contact, 23 directly in the ward, one made an appointment over the telephone and two made an appointment through another nurse. It is apparent that nurses, like doctors, avoid seeking out patients' families.

When asked what they thought of facilities for discussion with nurses and matters they would have liked to discuss with a nurse, 6 of the 27 relatives who had spoken with a nurse and 17 others offered comments. Three said they had no wish to talk with a nurse and another two said there were plenty available if one wished to see them.

"I went along to the desk and they always had time to talk to me. I could not praise them highly enough."

Of the others, 9 made comments on the apparent unavailability of nurses:

"I feel they don't want to see you and discuss the case as they are very busy. I don't like standing and talking in the corridor."

"Nurses conspicuous by their absence at visiting times."

"Any nurse seen always so busy I did not like to take up her time and no other nurse available."

The kind of comments that were made about the apparent lack of facilities for seeing doctors applied also to nurses:

"I appreciate staff is short and life is difficult for nurses but it would be helpful if there were set times to see staff."

"I would like to see a room where visitors can enquire regarding progress, treatment required and why."

Two relatives considered nurses inappropriate for discussing matters about the patient's illness:

"It's unfair to ask nurses about the patient's condition as it might undermine the authority of the doctor."

and some had found on asking that nurses were unable to provide the information sought:

"There are never any nurses about and when I did eventually see one every question was responded to by 'I don't know'."

"Facilities for seeing nurses are not required as they cannot supply any useful information."

"No one seems to be able to tell you anything at all."

These comments indicate that at least some of the relatives would have welcomed a fuller discussion with nurses and that they had learned that nurses were restricted in the kind and amount of information they would provide. As is usually the case in questionnaire data however, relatives who made comments, no matter their nature, were in the minority and most offered none.

Only 14 (13.3 per cent) of relatives had spoken with both nurse and doctor while 33 (31.4 per cent) had spoken with one or the other. It is to be expected that doctors and nurses would have different kinds of information and advice to impart yet a minority took advantage of this facility and only two relatives were offered it. The majority, 58 (55.2 per cent), had contact with neither doctor nor nurse during the patient's stay in the Department. When contacts with doctors include those outside the Department, 10 relatives (9.7 per cent) had had contact with a doctor prior to admission, as well as both medical and nursing staff in Radiotherapy. Fifty-eight relatives (56.3 per cent) had contact with at least one of the above, in four instances this being a nurse. The remaining 35 relatives (34.0 per cent) reported contact with none of these. The reasons such a large proportion should have no contact with health professionals have been suggested as at least partly due to situational constraints perceived by the relatives which interfere with motivation as well as a desire to avoid information which risked eliminating their uncertainties about the illness.

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CHAPTER 17

RELATIVES' ADAPTATION TO CANCER

In order to explore relatives' awareness, their desire for and sources of information in more depth, the spouses of patients undergoing radical radiotherapy treatment were interviewed. It was decided to limit the sample to one category of relative because, in such a small study it would not have been feasible to compare different kinship relations. Spouses were selected because it was assumed that they would be more likely to have contact with hospital staff. This was in fact borne out in the questionnaire study for contact between relatives and medical staff in Radiotherapy ($\chi^2 = 5.93$, d.f. = 2, $p < .02$ Table XXVIII, Appendix V) while relatives other than spouses were more likely to contact a nurse ($\chi^2 = 8.96$, d.f. = 2, $p < .01$, Table XXIX, Appendix V). It was also assumed that the effects on relatives of the patient's illness would be most pronounced among spouses, in the same way that bereavement has been shown to have differential effects.^(1,2)

Spouses of patients having radical radiotherapy rather than other types of treatment were selected. This group of patients were more likely to have a less complex history than, for example, most patients having palliative treatments or chemotherapy for conditions like Hodgkins disease who would show a longer disease pattern with more numerous hospitalisations. Such patients would present with varying prognoses but the nature of the treatment suggested that this would be relatively favourable and so patients in the advanced or terminal stages of disease were likely to be excluded.

Obtaining the Sample

The discharge dates of patients fulfilling the treatment criteria

were obtained from the nursing Kardex or, if not noted there, directly from nursing staff. In the third week of treatment patients were approached and it was explained that a study of facilities for visitors to the Department was being carried out. Patients had probably noticed questionnaires being distributed and it was explained that for patients having a course of treatment lasting a month or more and who were married, additional information was being sought about what life had been like for spouses in the patient's absence. Only relatives who visited the hospital at least once a week were included, and having ascertained regular visiting, permission was sought to approach relatives. No patient refused and later the spouse was asked to co-operate in the presence of the patient.

The Spouses

A total of 34 spouses apparently fulfilling the selection criteria were interviewed. Four were dropped from the sample, three because the patient turned out not to be having radical treatment and the fourth because of an unstable relationship where there was no intention of living together. One 'wife' was included although this was a common law arrangement which had begun long before the patient's illness. The patient regarded this woman as his next of kin.

The remaining thirty spouses were twenty-one wives and nine husbands. The difference in proportions is a reflection of visiting patterns rather than sex distribution among patients approached. Weekends at home for patients, shift work and distance to travel reduced the number of husbands who visited regularly enough to be included. The age range for spouses was 34 to 75 years, 28 being aged 65 or less and all social classes were represented.

The Interviews

A single interview was conducted in private in a small room on the ward or at the relatives home, whichever they preferred. Only three wives chose the latter. A standard introduction was given explaining the purpose of the interview as concerned with the effects on relatives of the patient's illness and the information they had received about it. It was pointed out that the researcher was a nurse but independent of the Department. Assurance was given about the confidentiality of the interviews, including that no information would be passed on to the patient or staff without their consent.

All interviews were recorded on an unobtrusive tape recorder after the spouses had given permission. None appeared perturbed at being recorded and only one made any further reference to it. The time taken for interviews ranged from 30 to 95 minutes, the majority lasting about 45 minutes.

During the interviews many relatives sought information. It was decided beforehand that if this arose, relatives should be encouraged to talk to staff. Why they had not done so already however provided a source of data and also, by reflecting questions back to relatives it was sometimes possible to explore the issue further. Another technique was to suggest that relatives were not unusual in asking such a question, that others had done so, and to try to ascertain the motive behind the question.

In two interviews wives became tearful. When it was suggested that the interview be terminated both chose to continue. Both women reported crying a lot when alone and attempting to cope with the knowledge of a poor prognosis in isolation. In another interview a husband showed his distress by avoiding all eye contact, although he

had been jovial and to a degree over-animated in his wife's presence in the ward. In view of this man's inability or unwillingness to communicate there was a minimum of probing. It was subsequently discovered that, while he reported no contact with doctors in the Department, he had in fact learned of his wife's extremely poor prognosis within the preceding forty-eight hours from the consultant. This information was first gained by chance from a patient. Unfortunately she would not disclose how she had come by it.

While a single interview may imply a relatively static picture of awareness, the relatives' descriptions of how they had become aware and how their desires for information had changed over time in relation to significant events indicated a dynamic process. The single interview can catch only a glimpse of this complex process but even so, the relationship between the spouses' interpretation of the facts and changes in their definitions of the predicament in which they found themselves was evident.

Relatives' Awareness

From the interview material, relatives were classified according to their current state of awareness of diagnosis and prognosis and their desire for information. The categories obtained are presented in Table XXX

It was apparent that relatives were more informed than were the patients themselves. All of the relatives except one showed at least some suspicion that they knew the nature of the illness and the majority, 22 of 30 (73.3 per cent) knew for certain that the diagnosis was cancer. Among those included in the suspicious category were those who said "I have a feeling it could be cancer", "I think that's what it is myself. But if they would just say he has it or he hasn't" as well as less explicit statements "I know that it's serious, her

being in here and having this treatment" which were associated with knowing the reason for radiotherapy. While those who hinted at the diagnosis may have been more sure than they were prepared to admit, their expression contained some degree of uncertainty and so they were included in the suspicious category.

TABLE XXX

SPOUSES' AWARENESS AND DESIRE FOR INFORMATION

| Number of spouses | Awareness of cancer | Wanted diagnosis | Wanted prognosis | Wanted further information on prognosis |
|-------------------|---------------------|------------------|------------------|---|
| 3 | Suspected | No | No | |
| 1 | Suspected | Yes | No | |
| 3 | Suspected | Yes | Yes | |
| 10 | Knew | - | No | |
| 4 | Knew | - | Yes | |
| 3 | Knew | - | - | No |
| 5 | Knew | - | - | Yes |
| 1 | Did not suspect | - | - | |

The one relative classified as not suspecting reported being told his wife had fibroids in the bladder and maintained this description. He spoke about his sister having had a breast removed and having radiotherapy but did not use the word cancer. Because it was not established that he suspected or knew, although he may well have done so, he was classified as not suspicious.

Developing Awareness

Knowledge or suspicion of cancer had come from a number of sources. At the time of first consulting the General Practitioner however, none

associated the patient's symptoms with cancer. Most were too innocuous:

I23 "The doctor told my husband there couldn't be very much wrong if he didn't have pain and he wasn't even getting up to go to the toilet at night. I thought myself he just had got a chill. I thought it was a germ and put it down to that."

I16 "As far as I was concerned it was just woman's trouble."

Referral to hospital, at times after what was perceived by some as considerable delay and for others immediately, was the first indication that it was something more serious.

I8 "She had this lump in her breast. I knew it could be cancer but I just thought she had knocked it or something. She was sent straight away and that got me worried."

At this stage it was suggested to one wife that it could be a tumour but no mention was made of malignancy. It was during and after diagnosis that suspicions really developed. There were two principal clues. One was the taking of a biopsy:

I2 "When they do a biopsy, there's only one thing they do that for."

It was the carrying out of the test rather than its findings which for some suggested cancer. Others realised it depended on the result and interpreted accordingly:

I5 "They took a tissue but when I didn't get the result and he wasn't sent for for three weeks I didn't think it was serious."

I33 "The Sister said 'we've got the result back and it's positive'. She said any questions you want to ask but all you think of is will I ever get him home again. She said that depends on whether he responds to the treatment or not. And that got me really frightened."

The other clue was that the patient was being sent for Radiotherapy.

I4 "When I heard he had to go for radiotherapy, I knew right away."

I32 "My sister had radiotherapy when she had a breast removed. I knew what it was for all right."

At the time of diagnosis half of the spouses had an interview with a hospital doctor. In two thirds of instances this was with

the most junior member of the team. All but four spouses saw a doctor only once and this was typically on the day of or the day preceding the patient's discharge. When relatives saw a doctor they were more likely to have been told that the patient had a tumour or 'active cells' than that the patient had cancer or malignancy.

I16 "He said it was the cells active."

I17 "It was a suspicious looking growth."

In fact no spouse had actually been told that the illness was cancer but the word malignancy was used. The diagnosis given, however, was usually sufficient to confirm that it was cancer among those who were already suspicious.

I20 "She went in and she had these abscesses. Well I got a wee bit agitated. I was all nerves then because the doctor called me into his room and told me about it. You see my mother died with cancer in the womb and in the bowel. I associated that and my mother not going to the toilet and when he told me she had the cells active I was away. I said to him, as far as I can recollect, 'Is it cancer?' He said 'there's active cells'. Well I couldn't tell you what he said to me after that because I pictured my mother."

Not all of the spouses who saw a doctor at the time of diagnosis reported being told however.

I29 "I saw Dr. U. the night before she was put out of Walker Hospital but they never told me they thought it was cancer. They never gave me a hint about it at all. He just said she was all right and she could go home. I was surprised at that. Surely they could have given me a wee bit hint, they could at least have told you subtly."

In the absence of an on the spot recording it is not possible to know what words were used, but what was reported constituted reality for the spouses. Interpreting that they had not been given the real diagnosis, some spouses felt that they had been misled.

I7 "When I went in they just said it was a straightforward operation and there were no complications. Every time I 'phoned they just said he was fine and there was nothing to worry about. Surely to goodness the hospital should have told me and not left it to my own doctor."

Revelation that the illness was cancer then came as a surprise when

relatives felt that they had been led to believe that the illness was not serious and been cured.

I18 "The funny thing was everybody was telling me how successful the whole thing was, you know. Every nurse that came in, just about everybody in general was saying how successful and how she never complained, you know... so there was nothing to discuss with the doctors as far as I was concerned. For the sisters and nurses were all saying how successful, and I never asked you see. It wasn't until the Wednesday and she was discharged on the Thursday, the wife said would I come in tomorrow at 11 o'clock and see Dr. McG. Now the lines I expected was 'Now your wife's gone through a very serious operation, try to help her as much as you can'. But she came straight out of the blue and said 'Your wife's got a tumour and we want to send her to... for deep heat treatment'. Well I was shaken, absolutely shaken. Up to this point they had been talking about cysts and all this carry on. It came completely out of the blue."

Being told it was a tumour coupled with the proposed treatment was sufficient to indicate cancer. When patients had to wait some time for admission for radiotherapy, this raised hopes that it might be a less serious form of the illness, or that it was not cancer after all.

I5 "When he had to wait all that time I thought I was wrong and it couldn't be. If it was serious he would have been taken right away. I'm just hoping now it's not a bad one."

Three spouses received diagnostic information from their General Practitioner. Two said it was a tumour while the third said:

I7 "'Of course you know he has cancer, Mrs. L?' Well you could have knocked me over. That was the first I knew of it."

Some General Practitioners tried to convey uncertainty about the diagnosis, 'it's a tumour but it isn't necessarily malignant', 'a tumour should never have been mentioned because we don't know exactly what it is yet', 'they are still not sure whether it is positive'. Such efforts were ineffective in the face of all the other evidence pointing to cancer. All of the relatives who reported at interview that they knew the diagnosis had learned prior to admission for radiotherapy.

They were far less certain about other aspects of the illness however and only five spouses (16.6 per cent) had been given any definite information about prognosis. In four of these prognosis was thought to be poor. In four instances the source of information had been a doctor concerned with the surgery performed on the patient while a general practitioner had given information to one wife.

I31 "At first they told me he had an enormous tumour and they didn't know if it was malignant. They said they would let me know in a week. When the week was up they sent for me. They told me it was malignant and that there's two kinds of malignant tumours. One the therapy can help and one that it doesn't help. They think he's got the one that they can help. But still they said he would only have about two years."

S.B. "Did you ask them to explain about the tumour?"

"No, not really explain. I was too upset to ask them anything really but they told me he might need another operation in six months but two years was all the doctor in Monkton said to hope for."

One spouse had been given conflicting information about prognosis:

I22 "I saw a different doctor after that operation. He said they thought he was going to be all right and I believed that you see. And then a fortnight ago I went to my own doctor because I sometimes take bronchitis and I went to get something for myself. He was sitting looking at me and he said 'Have you had any word from the hospital?' I looked at him and I said 'What do you mean, word from the hospital? Have you had word?' He said 'Yes, I had a letter'. I said 'Right then, let's have it, what's in it?' So he sat and explained it to me. He said the trouble - he said maybe he could last a year, maybe six months, but he said 'I really don't know what they're putting him through all this treatment for'. He couldn't understand this."

Relatives were more likely to have been given little information about the seriousness and extent of the illness or only a vague description.

I5 "I was just told a tumour, not where it was or anything."

I24 "He didn't say whether it was serious or anything to me, you know. Just that she's got a tumour and they're not 100 per cent sure of a cure but they can certainly stop it. Well it's logical, you can't say 100 per cent for any illness but haven't said where it is or what exactly it is. Whether it's really serious or otherwise. I had very superficial information."

The spouses had acquired their state of awareness in a variety of ways. Of the 30, 29 indicated at least some suspicion of the nature of the illness but for only 16 had this been confirmed by a doctor. In no instance had a nurse given a straight diagnosis. They had however used some of the euphemistic diagnoses - 'fibroids', 'thickening of the vocal chords', 'wart in the bladder' and nurses also imparted that biopsy reports had been positive. This information was interpreted in the light of other knowledge. One relative immediately interpreted a 'positive' biopsy as synonymous with cancer while another given similar information remained suspicious but uncertain about the diagnosis.

Still others had augmented their knowledge by conversations with friends and family. This was especially so among those who had learned the diagnosis and selectively obtained information which pointed to a favourable outcome.

I18 "Since all this happened I heard of a woman who had her stomach taken away and she carries a bag. But she gets dressed up in a bikini and goes swimming. Then this girl, a clerk in the office, she told me her mother had been in here and that was years ago. My own boss, I didn't know, but eight years ago he had a growth removed from the top of his spine and he's as sharp as a needle. All these people you never seem to hear about. It doesn't make it so bad as it first appeared."

Relatives were in variable states of awareness but in a more favourable position to extend their knowledge about the illness than were patients. It was apparent that their desire to do so however was associated with their beliefs about cancer and their current state of knowledge.

Relatives' Desire for Information about Diagnosis and Prognosis

Not all of the relatives wanted more information about the diagnosis or prognosis after the patient's admission to radiotherapy.

In fact 14 or the 30 relatives in different states of awareness expressed no desire to extend their knowledge. This included the single spouse who apparently did not suspect cancer.

Relative Who Did Not Suspect

His one attempt to discuss the illness had been with a staff nurse with whom he went to discuss his wife's return from a weekend at home.

I25 "I said was it very serious and she said it must be otherwise she wouldn't be in here. But she said don't worry about the treatment. It's very nice and there are no operations or anything else to worry about."

He had been visiting his wife when the Registrar appeared and from that encounter had gained the impression "There are no worries at all". His belief was 'everything is straightforward. The deep heat will dry up the fibroids and they will drop off'. He was perfectly satisfied with the information he had obtained prior to his wife's admission and saw no point in talking with a doctor.

I25 "There's no sense in talking to the big fellows. The girls are there - these nurses can probably tell you more than some of them. I think they are usually more informative than the actual practitioner is."

The attempts to convey that there were no worries apparently succeeded in that his wife's illness gave no cause for concern. This being the case there was no need to consider that the prognosis could be anything other than favourable.

Suspected Diagnosis But No Desire to Have Suspicions Confirmed

The next group comprised the three spouses who suspected cancer but who had no desire to have their suspicions confirmed. They sought to avoid information which might tip the balance to confirm cancer. Accordingly none had engaged in conversation with hospital staff. One wife whose husband had a tumour of the pituitary gland had achieved

this by placing all responsibilities on her son.

I28 "They haven't told me anything. It's my son saw the doctor. They kept it all back from me not to have me worried."

S.B. "What did your son tell you about it?"

I28 "He said he would have been blind in three months if it hadn't been done. The blackouts were due to this thing in his head. It always showed up on the X-ray plate. It was getting bigger and he was gradually losing his sight. They did the operation to remove it."

S.B. "Has your son said what it was exactly?"

I28 "No, he hasn't told me what it is."

S.B. "How do you feel about that?"

I28 "I don't know really. But I think it's better not knowing the right thing. All I know is he would have been blind in three months."

She had avoided any discussion about the illness.

S.B. "Do you feel now you would like to know more about it or are you satisfied as it is?"

I28 "Well my son hasn't told me an awful lot. I've just always been wondering what it is. But you just don't know who to speak to about it, you know. I think I'm better as I am."

While she wondered she was not prepared to take any positive action either with her son or to see a doctor. Nor could she without risking having her suspicions confirmed.

I28 "It wouldn't do any good to know. I'm at work just now and if I knew the right thing I'm sure I wouldn't have managed all this time. I'm sure they've kept it all back not to have me worried. If I saw a doctor I would just get more worried by what he would say."

Others similarly were disinclined to seek out a doctor for fear of having their hopes dashed. That the doctor had not asked to see them also helped support the belief that it was not something serious.

I26 "Sometimes I wonder what's wrong, you know, if it could be a touch of cancer. But then I say to myself if it's right serious they would ask to see me and nobody has. If it's not - well I would just rather wait until they asked for me to see them."

S.B. "Does this mean you prefer not to know what it is?"

I26 "Well, I'm torn one way and the other. I keep wondering and worrying. But if I knew that it was going to turn out all right I would like to know but if it's bad I don't. I think it's best left up to the doctor. If it's necessary they'll ask to see me. On the whole though I think I would rather stay as I am."

While these relatives had no desire to have their uncertainties over the diagnosis removed because of the connotations cancer held, another group who knew the diagnosis did not wish to know anything about the prognosis.

Knew Diagnosis, Did Not Want Prognosis

These ten relatives were working on the assumption that, since they had been told or otherwise learned the diagnosis and had no information to suggest that the prognosis was bad, then it was better to retain the belief that it was good.

A husband whose wife had carcinoma of ovary said:

I18 "Well there's no point in knowing any more now she's got this. It wouldn't have been helpful. How can I put it - it's in the hospital's hands now isn't it? I can do nothing, absolutely nothing. So if I was told it was a big one I would be in a worse state than what I am just now."

S.B. "And if it isn't so bad?"

I18 "Well if I was told it was a small one and it would be cleared up and all the rest, then I would take the same line I'm taking now. I'm just taking the middle of the road. I don't know how to put it. A little knowledge is a dangerous thing. And from these people you only get so much information."

S.B. "Is this your expectation?"

I18 "Yes. I mean a consultant isn't going to tell you if it's a big one or a small one. I'm better just to keep on hoping and steer clear."

Beliefs about cancer suggested that they would be unlikely to receive encouraging news and so it was better to maintain the current outlook about prognosis. A wife who knew her husband had carcinoma of bronchus had had no contact with either medical or nursing personnel.

S.B. "You say you don't feel you want to see a doctor here?"

I32 "No. There's no need. I know it's cancer. I just hope that there's some hope for him. I'm hoping that it will have done him some good and he'll at least be spared to me for a couple of years."

S.B. "You wouldn't rather know for sure what the doctors think about the prognosis?"

I32 "I don't think so. After all it could be bad and I wouldn't want to know. I'm looking to a couple of years. If the treatment burns it out so much the better. I'm just going to wait and see what happens."

Though cure was hoped for, this wife set her sights on what could be regarded as a poor prognosis. Yet she would not risk hearing a worse one and so avoided asking.

Relatives Who Said They Wanted More Information

While 14 spouses indicated that they did not wish to extend their knowledge, the remaining 16 spouses all expressed a desire for more information about the patient's condition. Yet only 6 of these had had some contact with medical staff. In one instance this was limited to an informal approach to the house officer. Linguistic difficulties had precluded the wife obtaining any information, the doctor being unable to interpret her questions. One other spouse was making an arrangement to see the doctor. This leaves 9 spouses who said they would like to know more about the patient's condition yet have not sought out the most likely source of such information. Why should this be?

One reason given was that it was not possible to come to the hospital during the weekdays when doctors were likely to be available.

I16 "I would like to know how serious it is but I come up at weekends and there's no one here to ask. The nurse I asked said she couldn't give me any information. I would have to see the doctor but there isn't one. And it's difficult in the week. It's not just losing work but it takes at least five hours."

S.B. "Have you tried to talk with the doctor at Walker when he goes there to the clinic?"

I16 "Well maybe I could 'phone there but it's not the kind of thing you can discuss over the 'phone either. I'm not complaining mind. When I asked the Sister and she said she couldn't tell me, I quite understand this is not a Sister's job and she's not allowed to give information like that. It's up to the doctor isn't it?"

S.B. "That would seem to be the case."

I16 "Well I tend to assume it is the doctor's job. In cases like tumours it is the doctor. But in cases like mine when they can't get in I think they should make special allowances, or write a personal letter. I think the doctors should inform us a lot more than they do."

Others also commented on the apparent absence of doctors in the ward whom they could ask:

I17 "Well I've never actually seen anyone to ask. I'm pretty sure it is (cancer) though without asking. Maybe it would be better to have a talk with the doctor. But there are never any about."

It was not unusual for relatives to postpone their visit to the doctor until the end of treatment with the expectation that some definite pronouncement on prognosis could be made then.

I5 "You wonder if it's cancer and if they've got it in time. I'm frightened about that. What's going to happen. I feel frightened but I don't know why."

S.B. "Have you actually spoken to anyone here about your fears?"

I5 "No. I was waiting until the treatment finished to see if it has cleared up what's there."

S.B. "Have you arranged to see someone?"

I5 "I will do that today. Dr. P. is the consultant. I'll see him."

S.B. "Have you spoken with a nurse?"

I5 "No. There's no point really. The doctor will tell me all about it."

S.B. "Do you want to know the details then?"

I5 "Yes, I've been worrying a lot. I think if I knew one way or the other at least I would be sure. I'm hoping it will be good news of course but I still think it's better for me to know anyway. I can only hope this treatment has worked."

While this woman was sure she wanted to dispel her uncertainties about the diagnosis and prognosis, although she was almost certain it was cancer, others who knew the diagnosis experienced greater conflict over whether to enquire further.

I27 "I've never seen a doctor. I know I've been wrong. I would like to see him but I was frightened I would hear something I didn't want to hear."

S.B. "What kind of thing?"

I27 "Well I don't know how serious it is. I'm just hoping and praying that everything will be all right for him."

S.B. "What makes you wonder if it is serious?"

I27 "Well he's getting this radiotherapy treatment. That's for cancer and that's what I think he's got. I know myself it's that. When I heard he was to come here I thought things aren't looking too good. I know I should have asked about it by now."

The dilemma facing this woman, whose husband had lymphosarcoma, was obvious. She felt she should have enquired but daren't risk receiving bad news. She had made a tentative enquiry through her brother when she became really concerned about her husband who was suffering badly from the effects of radiotherapy.

I27 "M. was very poorly one night. I was really worried so we 'phoned the ward. My brother did it for me. He asked Sister what the position was. He told her his wife was worried but she said I would have to make an appointment to see the doctor."

S.B. "Have you done this?"

I27 "No. It's not every time I can get in. I depend on a lift because I can't manage the buses." (Due to arthritis)

S.B. "What would you like to discuss with the doctor?"

I27 "I want to see if this has helped. Could they cure it? This is what I want to know, can it be cured?"

By expressing in this way, we see that she wants to know about the future in terms of whether the illness can be cured rather than its converse, whether it cannot be cured. Rather than risk the latter she continues to suffer the agonies of uncertainty. That she had

not arranged to see a doctor, while partly attributable to difficulties in getting to the hospital during the day when transport was not available, is markedly associated with her perceptions of cancer.

I12 "When I knew it was a tumour, you know it was like a death sentence. That's how it felt to me."

S.B. "How do you feel about it now?"

I12 "Not so bad. I've heard of cases that have been cured and back to work. You still don't know. You're left hoping that it will turn out all right but you don't know."

Fear of what she might hear, that it may destroy what hopes she had, discouraged seeking information. The one enquiry to nursing staff occurred at a time of great distress when, apparently, fears for her husband's life were greatest. His relative improvement caused these fears to abate and with them the desire to face the truth.

It was interesting to note that several of the spouses had, in their own minds, put some time to the prognosis without ever having discussed it with a member of staff.

I33 "He says to me he knows he's on the road out so I just say 'and so am I'. I don't give him any cuttings. I wouldn't let on. I think myself it's likely to be something like six months but I would never say anything like that to him. We always just shove it to the side. Of course as I say we're ignorant of the trouble and we don't know, but..."

For some, however, prognosis had already been given prior to admission and some spouses wanted further information. One had resolved to see her husband's surgeon after the completion of treatment. She had already sought him out and considered that:

I2 "...he was very frank and open about it. He actually drew a diagram to show me where the trouble was. He gave me very good hope. He said it was a very small area and as yet there was no spread. The treatment would probably arrest it. He gave me good hopes for radiotherapy."

Armed with this optimistic prognosis she had resolved to pursue her information seeking with the helpful surgeon rather than the unknown radiologist.

Three other wives who had been given a prognosis also said they would like further information. They were in a different category however since they had been informed of a poor outlook prior to admission to radiotherapy. Not unnaturally all hoped to be told that the treatment given their husbands had improved matters.

One wife had been told by a houseman immediately prior to her husband's discharge:

I21 "It was malignant and nothing can be done. The pain would get gradually worse till the end. You'll just have to be brave and wait."

Her husband's General Practitioner had been instrumental in arranging further treatment. The wife had made no moves to talk with anyone about her husband, although she said she would like to:

I21 "Yes, I feel now that the headaches have eased that I would like to know what's what. At first they said they couldn't do anything but now he's had this done and it's eased the pain. I would like to know what's the expectancy of the treatment. Can he have more if he has to? Is there any chance of doing it again if the pain comes back? Our own doctor thought the treatment might just prolong life and not be a complete cure. But it depends on what treatment he can stand. I can see if he could only take five treatments this would be of very little help, whereas the more he can take the better."

S.B. "Have you arranged to see anyone to discuss this."

I21 "No. I don't think there's any point until after this treatment has finished. I'll try to see him at the Grange when he goes there. I felt everything was so hopeless before he came here. Now I just have to keep hoping."

Similarly the wife who had been told by her General Practitioner 'Maybe he could last a year, maybe six months' felt she would like to know the score from those now treating her husband.

I22 "I would like to know how they feel this treatment's working. He's away for an examination just now with Dr. W. and I would like to know what he thinks, for it's something that you've really got to know, isn't it? What's in front of you. I mean we've all got to die sometime. We've had a good life. We've been married 38 years and the way they spoke to me at home I don't think he's going to last very long. I would really like to get this verified, to find out here what they think."

S.B. "Have you been approached by anyone here about it?"

I22 "No. Anyway it's my place to approach them. It's not as if he's critically ill. He's just getting this treatment. I was quite happy with the situation as it was if my own doctor hadn't told me that. That really upset me, that's why I would like to get hold of one of the doctors here to find out how it's going."

While desiring more news, and hopefully a less bleak prognosis, this wife also found difficulty in making the approach.

I22 "I don't know how to go about it. When you come in the desk is surrounded by nurses. I say I'll see about it today. But I never seem to get round to it."

Thus while they hoped for a more optimistic outcome than they had been led to believe was the case, these wives had not yet summoned enough courage to find out. The remission of symptoms had raised hopes as had the fact that something was being done. Seeking further information may have dashed these developing hopes for the future.

Of the five spouses who had actually discussed the patient with a doctor in Radiotherapy one still remained in a state of ambivalence about seeking a prognosis. While she stated that she wanted prognostic information she had made no definite effort to secure it. Twice she had stopped the consultant in the ward or on the stairs but she had not made an appointment for a more private conversation.

I10 "Dr. G. also said it was a tumour and it was malignant. I got that from him so in a way I didn't want to know any more. And yet I'd like to know what this treatment is doing for him and if it has reduced the glands. He's certainly less full than he was. What's going to happen? Is it going to come back again or what? You see all these things you'd like to talk about with someone."

S.B. "Have you arranged to see Dr. G. again?"

I10 "No. I think I may see him before Mr. B. goes home. But I don't think the doctor can say with any real authority that your husband will be all right for the next two to three years because anything can happen to any one of us. But on the other hand is it going to be a very short term thing, this relief he's got? On Monday he will have completed thirty treatments. I don't know about further treatment after he goes home. And I want to know about that. On the other hand he will be followed up and we can go to the clinic. So in a way I feel it may be unnecessary to have a talk with him now."

She did not want to hear a prognosis in terms of years but, while some idea of the time scale would have been welcomed, she was not certain about whether she should pursue it.

The remaining four spouses sought out a doctor and attempted to learn the prognosis. One of these was dis-satisfied with the quality of information given her.

I15 "I've been to see him twice. The week E. came in and then yesterday. But he said he had nothing new to tell me. That's no way to treat somebody."

S.B. "How do you mean?"

I15 "When I went in and I asked about the treatment he said he couldn't say. Well that's ridiculous. How can you have all this for a month and not be able to say at the end of it. That's what I got told."

S.B. "What did Dr. P. say exactly?"

I15 "He said he couldn't say how bad it was or if it was cured. I would have to wait for two months for any results. But it wasn't what he said. It was how he said it. He was arrogant and inhuman. That's no way to treat people especially when it's obvious you're worried. People like that have no right to be doctors."

S.B. "Did you feel that you were given enough information?"

I15 "No. I definitely would say no. Nobody here, relatives or patients are told anything about what's happening. If you ask you are likely to be told 'we don't know'."

Her beliefs about lack of information in the department extended beyond prognosis. She had been irritated by changed decisions about whether her husband could go home for the weekend and the number of

treatment fractions. She herself had been successfully treated for skin cancer some years previously but her father had died of cancer. At one point her husband was in such a poor state that she thought he too would die. She expected some unequivocal prognosis at the end of her husband's treatment together with plans for his future care. When she did not receive either, she attributed this to the doctor's waywardness rather than to possible clinical uncertainties surrounding the illness. The uncertainty for her was intolerable yet she could find no way out of it. Hospital staff had not resolved it nor had they given her anything to suggest a hopeful outcome.

This was not so for the other three spouses who sought out a doctor and were all given a prognosis which they interpreted as optimistic.

I7 "He explained everything to me. He was very kind. He told me that they had found the growth when they first did the operation and that this was a new kind of treatment. According to Dr. T. I'm not going to give up hope completely. He's told me they can't cure him. This treatment, they didn't do it until recently and that's why he didn't get it right away when they discovered it (the tumour). If it works, and they're hoping it will, it can give him another two to three years. Well a lot can happen in two to three years. They can break through to something else so actually, after my interview with Dr. T. on Thursday I felt he had given me a legacy."

S.B. "Did you ask to see him or did he seek you out?"

I7 "No, I made the appointment through the nurses."

S.B. "Why did you want to see him?"

I7 "I felt I had been kept in the dark and I wanted to know. You see before this, before he came here and he wasn't getting any better, sometimes I would get angry at him. I thought he wasn't trying to get well. But then I thought the operation had been the end of it all. Then I found out about the cancer and he was to get this treatment. I thought I should at least find out what it is going to do for him. Dr. T. explained everything."

Finding out about the prognosis, while cure could not be established with certainty, provided a more hopeful picture than had originally been thought to be the case. This happened with other relatives too.

I24 "When I saw Dr. T. he asked me what I had been told. I explained that I had been told it could be one of three types of tumour. Dr. T. said it was the worst type, it was progressive. But he said we think we've covered everything, it's pretty accurate, but we can just miss a bit. Just one particle could be left and away it goes again. He was worried about her pains. She had a bone scan. He told me if there's any disease in the bone, that's it. He more or less told me. But when the results came they were negative so that's a relief anyway. He said 'All I can say to you is that she has a reasonable chance, one in three, if we've got everything in here'. He said 'I could say to you she's cured' but he said 'we can't until we see what happens after the reaction settles down.'"

This prognosis, while implying an uncertain outcome, was still more favourable than had been believed.

I24 "Well I felt it was hopeless but when he told me some people are cured I thought this was marvellous, you know. I never ever thought there was a cure. Because J. herself asked the ENT man or the radiologist if what she had could be cured and he said they didn't like using the word cure. That's how I was surprised when Dr. T. said that to me. He said 'If we've got everything in here I could say she was cured'. I never knew that. When he said a reasonable chance, one in three, I thought that was pretty good really. I asked Dr. H. (G.P.) what will happen if it starts again? They'll just give her some more treatment, and it won't be so bad if they're keeping a close watch on it."

Those three relatives who sought prognostic information and remained hopeful were already aware of the diagnosis. They learned that there were different kinds of cancers, but the prognosis was better when there was no spread, that new treatments were developing and that more treatment was a possibility in the event of spread. No promise of cure was given yet they were all more hopeful of a successful response to treatment after their conversation with the doctor than they had been before it. While they were aware that cancer could kill, and all had had family experiences of deaths from cancer, two relatives considered that the patient's tumour had been

caught early enough for it not to have spread.

- I29 "It was a blessing in disguise it touched the vocal chords. That's what put them on the track of it right away so they got it early. She never had any pain or anything and she looks so well. Nature works in funny ways."

The belief that the cancer was in its early stages suggested that it need not be fatal.

- I24 "I asked the doctor in Frankham if it had been there a very long time and he said 'I very much doubt it'. You see with it being where it was it showed up quickly."

Also encouraging information had been obtained elsewhere about prognosis.

- I24 "My wife asked the G.P. if he could cure her. He said 95 per cent cure and 5 per cent not quite cure. He wouldn't have said that without some foundation."

With such beliefs of a hopeful outcome going to see the doctor was relatively unthreatening. It was unlikely that the doctor would convey bad news. In such circumstances, it was not surprising that facing up to reality was less difficult than for those whose beliefs about cancer indicated an inevitable and painful death.

- I29 "My son's father in law died of cancer. Nobody knew what it was until two to three days before he died. A locum G.P. told the family and it was a nasty shock. So I think it's better knowing. There's no point in burying your head in the sand. It's better to face up to reality."

Like patients, it was evident that relatives engaged in selective information seeking and avoidance. This related to their beliefs about cancer in general and the patient's illness in particular. Relatives on the whole however were more informed about both the diagnosis and prognosis although not all had learned from formal sources. The extent to which relatives were so informed depended largely on whether they were prepared to take the initiative to enquire.

Some Consequences for Relatives

While it was not the intention to study the more generalised

effects on relatives of having a patient with cancer in the family, so potent were some of the experiences related during the interviews that they are reported briefly.

Half of the spouses had in fact visited their own General Practitioner during the previous month. While some suffered on-going physical complaints most striking were upsets created by anxiety about the patient. In all eleven of the thirty relatives made specific statements about feeling anxious or being troubled by 'nerves' while another fourteen described behavioural changes indicating anxiety.

I14 "I'm always doing something. I will just take half my tea then sit down and read the paper and then do something else. I can't seem to be at peace. I can't read the paper."

I12 "When I'm at home I don't feel like doing anything. I can't settle. Then when I get to the entrance of the hospital it's like somebody winding me up again you know."

Changes in sleeping habits were particularly marked - difficulty in falling asleep and early wakening. The quiet of night was described as the most difficult time when thoughts about the patient flooded consciousness. One wife described how she had worked out all the funeral arrangements while lying awake. Some had readjusted their work to keep them out of bed until the early hours while one wife had taken to doing housework during the night when she could not sleep. Another was afraid to go to bed in case something should happen to her husband and she would not hear the telephone ring. She had continued a regime of visiting her husband afternoon and evening for several weeks, walking in the street between visits because there was no time to go home, eating little but smoking a great deal. She appeared close to exhaustion.

Increased alcohol and cigarette consumption was mentioned and three wives reported crying a great deal when alone. Others reported how, during the day at work, thoughts about the patient recurred.

- 13 "With my job (female bus driver) you've got to stay alert. I try to find things to do at home and sort of try to think about other things. But when you're driving along it all comes into your mind. You think how could he possibly have cancer when he's led such a good life."

Some of the spouses were engaging in what Janis⁽³⁾ has called 'worry work' - the potential outcome of death being entertained and giving rise to anticipatory grief and mourning for the loved one. In interviews spouses recounted good times of the past, one even bringing her honeymoon photographs to show. Another already referred to her husband in the past tense.

Much of the stress was created by the spouse's own lay knowledge of the illness and the treatment while uncertainty about the future exacerbated fears. The idea of the patient wasting away and suffering pain was salient. Radiotherapy was associated with ideas of scarring, burning out and causing extreme discomfort both physical and mental. Depression after radiotherapy was entertained and one wife was afraid that her husband would go to a mental hospital, believing the effects of radiotherapy were so drastic.

What to expect of the patient after discharge also created tensions. One wife saw her husband's incontinence as abhorrent. Behaviour and mood changes after neurosurgery were frightening. What would a wife do if her husband choked?

Reactions of family and acquaintances at times added further to the stigma associated with cancer.

- 124 "Having an illness like this is not a thing you can talk about. You know some people at home say 'How is she?' and I just say she's responding to treatment and she's getting on fine, this sort of thing. But a lot of people think that's what she's got and of course they're right. But there are stories going round that she's had a big operation and there's no hope. Then there are other stories. One woman I met asked me how she was and if she had an operation. I said 'No, just radiotherapy treatment'. And she said 'Oh, there's no hope of course'. This is how they go on. It's great what they say to you isn't it?"

Some family members avoided any discussion when the spouse would rather have spoken about the patient. In other instances it was the spouse who wanted to protect family members by avoiding discussion. The problem was further compounded for some by not knowing how to deal with the patients and not knowing their state of awareness. Fabricating stories to conceal the nature of the illness led to later doubts about the worth-whileness of having done this and how the patient would feel should they find out. Some experienced guilt at deceiving their spouse, but felt that this was still preferable.

I10 "If he's going to die I certainly don't want him to know anything about it. But I've never deceived him before."

Not all felt like this of course. Some couples had a tacit agreement not to discuss it at this time.

I32 "He knows and I know and we just leave it like that."

Others had tried to protect each other but eventually the truth was brought into the open, providing a basis for a more constructive relationship to deal with the adjustments created by the illness.

But even among those who had been 'open', private areas of fear still existed. What if the treatment did not work? What if it had spread after all?

Sources of Support

While in some instances the couples supported each other, more often relatives turned to some friend or other family member with whom to share the burden. It was the latter more than professionals who constituted the primary source of sustained help as well as sometimes acting as lay consultants.

I27 "My son and daughter know their dad has a tumour but I don't talk to them about it. I don't want to worry them. My sister

and brother though are different. It does me good to confide my worries to them and they say how wonderful the things are that they can do now and it does me good to hear that. Since he's been in here I've heard of a few cases of people that have had radiotherapy and they're back at work now. I think people are trying to console me by telling me this."

Not all spouses were fortunate enough to have this support available to them and indeed not all felt they required it. By comparison those who, in the past, had relied on the patient as their sole confidante felt very isolated.

I15 "We've no family and our parents are too old to worry with this. And if I told his sister they would just make a fuss, so it's just me. But last week I thought he was going to die. In fact I said goodbye to him, he was so low. I saw the minister. He was good to me but it's not the same. You can't go running to him all the time."

I9 "I haven't been able to talk to anybody. I hadn't really realised it was as bad as this. The doctor said about two months. His family just upset me. I feel all alone. I've just not been able to open up to anybody."

In all six spouses were dealing with their problems alone while saying they would have welcomed the chance to share them.

Only one spouse said he had received substantial help from a professional, his General Practitioner with whom he had weekly 'counselling' sessions. The spouses generally held low expectations about the role played by doctors and nurses in this domain and considered it more appropriate to call upon their own social network for help. While five spouses had had some contact with a social worker either at home or in hospital they were regarded as providers of benefits in the form of money or housing rather than other forms of help.

During the patient's stay in Radiotherapy, none of the spouses had found that nurses had been helpful to them other than in matters of arranging weekends at home or in providing superficial information about the patient's progress. Nineteen of the thirty had had no

contact at all with nurses in Radiotherapy and a further three had only the briefest of social contacts, described as 'just saying 'hello' in passing'. Contact was restricted to the telephone for another two. The six spouses who had had face to face conversations with nurses described them as brief and public. In each case it was the spouse who had initiated contact and nurses imparted little information either about the illness or managing the patient.

I4 "She just said he was getting on well with his treatment but it would be better to see the doctor. She didn't really tell me anything."

I31 "I'm wondering how I'll ever manage when he gets home. He's so jumpy with the kids. Nobody gives you any advice about this sort of thing."

Yet relatives were soon to be faced with a number of practical problems directly associated with the illness which they spontaneously raised during the interview - incontinence, fits, special diet, return to work, sexual activities, skin irritations. Other short and long term problems were also influenced by the patient's illness - who would run the farm, coping with a mentally handicapped child, increasing blindness, looking after aged parents. The relatives were having to cope with these problems as well as their own feelings about the future.

These data indicate that, apart from information about the illness, which not all relatives wanted, some would appear to require much more in the way of counselling and practical help to manage. Significant gaps in both of these areas indicate that nurses in the setting studied were not prepared to bear such responsibilities. Why should this be the case?

Nurses Avoidance of Relatives

The simple answer of course would be that nurses did not have

sufficient time to spend with relatives. It was often the case that nurses worked under extreme pressure to get through their routine tasks. Even during less hectic periods however, the pattern of interaction between relatives and nurses was maintained. Nurses always perceived themselves as working under pressure, even if the ward was not too busy some emergency could be brewing up which would take all of their time and so they had to be in readiness. Whatever the facts of the matter, nurses' beliefs were that they did not have time to become involved with relatives. Had they perceived such time existed, and it did occasionally, there were other factors which caused nurses to avoid relatives. These were associated with nurses' beliefs about their role vis a vis relatives and their preparation for this role.

The same kind of explanation holds for nurses' avoidance of communication with relatives as held for patients.

While nurses believed that relatives had a right to be informed about the patient's illness, telling was the province of the doctor. Relatives who asked were advised to see the doctor. But information about the illness, while being only part of the story, coloured nurses reactions to relatives. While relatives at interview indicated a desire for different kinds of information and expressed a need for support stemming from their beliefs about cancer and knowledge of the patient's illness, nurses did not know how much relatives knew and they feared disclosing while at the same time believing that relatives should know. What relatives knew tended to mean what relatives had been told and since this was never discussed with doctors, apart from asking the relatives, nurses had no way of knowing. They were afraid of overstepping the institutionally defined boundaries.

In other words, nurses associated anything other than the most superficial conversation as likely to contain some element of the nature of the illness or prognosis. They were not prepared to risk entering into such conversations. This meant that they avoided showing interest in relatives' concerns by not seeking them out. Relatives were left to make the approach except when there was some organisational matter to discuss or the doctor wished to see a relative and a nurse passed on this information.

By always seeing relatives in public places, as well as reducing the likelihood of them raising topics difficult for nurses to manage, this also minimised the risk of emotional outbursts. Thus nurses avoided relatives in terms of establishing contact and encounters were maintained at the most superficial level. The interviews had demonstrated that relatives could show emotion and expose their feelings about the illness and the future should privacy be arranged. Such situations would have proven difficult for the nurse to manage and it would have been difficult merely to have referred the relative to a doctor.

The absence of training in the management of relatives was apparent. Some relatives were suffering acute anxieties and anticipatory grief without the benefits of professional support. There existed an inability or unwillingness on the part of nurses to consider sources of help, including information, which could have assisted in relieving some of the problems being experienced by relatives as something distinct and different from information about the diagnosis and prognosis. Nurses did not perceive the need to nurse relatives. Based on their experiences of little help from nurses and a desire among some relatives to avoid confronting the illness, most relatives did not seek them out. In the absence of a strategy to ensure contact between nurses and patients' families, relatives constituted an unaccountable area of nursing care.

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CHAPTER 18

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

SUMMARY

This study set out to describe and explain communication about cancer in a single hospital setting. The focus was in the processual and interactional nature of communication about the illness together with an assessment of the beliefs and assumptions of hospital staff. The patients studied were at different stages of the disease process, had been diagnosed elsewhere and varied in how much they had been told about their illness. The developmental nature of patients' adaptation patterns to cancer during their stay in hospital and the process of communication in relation to awareness and the management of information by all categories of participant were examined.

Doctors were universally regarded as the most legitimate authority to impart diagnostic and prognostic information. In practice they seldom did so. This was based on a belief that the majority of patients should not be told. It was assumed that patients had no desire to be told and that telling those who did not already know would precipitate a bad reaction. There was no point in destroying hope by telling. This view co-existed with an acknowledgement that some patients would want to know and should be told, so long as they would not react unfavourably. The difficulty of determining which patients fell into this category resulted in patients not being told unless pressure was exerted to do so.

Doctors were faced with uncertainty over which patients had been told, which genuinely wanted to know and their likely response to telling as well as over some of the clinical features of the illness. The beliefs and assumptions held about patients gave rise to routinised

communication which also served to manage uncertainty. These routines were not made explicit by doctors but were apparent from observation of their interactions with patients.

Routines limited the amount and quality of information given to patients by increasing uncertainty over diagnosis while implying certainty over a favourable outcome. Routines were specific to particular categories of patients based on diagnosis, stage of the illness and treatment. Typifications therefore were grounded in features of the illness rather than in characteristics of the patients themselves.

Routines had evolved over time and had to be learned. Senior doctors were familiar with them and used them to resolve the difficulties associated with the uncertainty inherent in communication. Short stay junior doctors on the other hand had not had the opportunity to learn the appropriate ward routines and had no formal training in their use. Nor could they have had because routines had not been articulated. Thus while senior doctors could ensure consistency in communication between patients and for the same patient over time, junior doctors created inconsistencies by what they told patients. The availability of routines permitted maximum manoeuvrability in the process of communication by the judicious use of uncertainty but junior doctors limited this by emphatically denying cancer or confirming it - something consultants would do only in exceptional circumstances. These difficulties rarely emerged. The consultants' over-riding authority in communication meant that they saw no need to discuss it. The potential conflict which would have been generated had junior doctors reported their actions resulted in them also avoiding such discussions whenever possible.

Nurses were similarly excluded from decision making over what to tell patients or learning what had been told by consultants. Doctors and nurses alike did not consider telling as relevant to nursing, although nurses reported that they would have liked information regarding what patients had been told as a basis for reducing uncertainty over other aspects of communication. They were aware that few patients were informed and, on the whole, they shared the doctors' perspectives in telling. However they asserted that more patients should be told than was currently the case particularly patients who indicated awareness, but they were not prepared to over-step professional boundaries and disclose. Disclosure by nurses occurred on very rare occasions and only the most senior staff would formally do so.

While they believed that disclosing diagnosis and prognosis was not a nursing function, nurses were faced with questions about such matters. These usually took an indirect form, and wherever possible nurses avoided disclosure by employing the same routines as doctors. Like junior doctors however, some nurses and students were not aware of appropriate routines and so, they too created discrepancies in information given to patients. Nurses who were unable to respond to patients with some appropriate information could always refer patients to a more senior nurse or doctor as the legitimate authority with whom to discuss their question.

Nurses therefore were not faced with many uncertainties over telling but they were faced with similar issues regarding talking about the illness with patients. Just as some patients would benefit from knowing, some would benefit from airing their concerns but they were uncertain about whether patients really knew as well as how they would react to openness. They assumed that most patients would react badly. In the face of such uncertainties nurses adopted a common policy of avoiding openness about the illness, thus reducing the risk of possible

disclosure and adverse reactions. Avoiding touching on the illness was accomplished through minimising prolonged and private interactions with patients as well as through the management of conversation with avoidance of expression of feelings or concern. With remarkable success, nurses managed to maintain a happy ward atmosphere in an attempt to create the illusion patients had little to worry about.

Contrary to data obtained at interview, observation together with nurses' reports of their interactions demonstrated that nurses did not base their communication on individual patient characteristics. Nor was any known theoretical basis apparent upon which nurses acted. The absence of patient assessments as a basis for communication was similarly reflected in nurses' ward reports. In these ways nurses managed interaction and communication, avoiding disclosure and openness about cancer, believing that they avoided many of the problems they anticipated would arise should openness about cancer prevail.

On admission the majority of patients already knew or suspected that they had cancer. Awareness however was more often expressed at a level of suspicion rather than certainty, especially over prognosis. Patients managed the uncertainty generated by their suspicions in different ways. Rather than attempting to establish their diagnosis as had been originally hypothesised, many patients preferred to maintain uncertainty with a minority making a determined effort to establish the truth. It was the maintenance of uncertainty over diagnosis and prognosis which for many permitted the continuance of hope.

In order to construct and maintain an amenable interpretation of their illness, patients were actively engaged in selective information seeking, avoidance and rationalisation. Through these processes they attempted to establish an interpretation of their illness through

which they could cope. As well as what was told formally about the illness, patients relied heavily on informally obtained information which was amenable to a greater degree of control in terms of both acquisition and interpretation. Patients who wanted to establish the truth sought it informally as well as formally.

Because of the connotations of cancer, most patients sought to maintain the comparatively low level of anxiety generated by uncertainty over diagnosis. Others however eradicated uncertainty. A few denied that the illness was cancer while others established their diagnosis. The latter were able to do so while maintaining optimism. Although some had no hope of recovery, they were far from despondent. This behaviour is consistent with Maslow's⁽¹⁾ general description of the management of uncertainty. When psychological and social factors increase fear and anxiety beyond that generated by uncertainty itself, only then is a state of uncertainty preferable to achieving certainty. Otherwise attempts are made to reduce uncertainty.

Those whose coping strategy was to seek diagnostic and prognostic information encountered difficulty in obtaining it directly from staff. However, they were often able to deduce the facts from what was told them by reading between the lines and placing their own interpretation on the euphemisms used. They also relied to a great extent on cues and the informal network. Other patients were available, not only as a source of information, but also to clarify the situation and resolve problems. In this context discussion between patients was characterised more by mutual reassurances than frankness, but permitted expression of concerns. This was the case particularly among those who knew that they had cancer and were seeking to express their feelings.

While the communication practices of staff, which sought to avoid reference to cancer or its implications, were not helpful to patients

who attempted to acquire information or mutuality, they did succeed in perpetuating denial and the maintainance of uncertainty.

Communication with fellow patients likewise did not destroy these types of adaptation but they were sometimes put at risk by patients who coped by sharing their worries. Coping with cancer by denial or maintaining uncertainty was not a matter of ignorance but of what patients were able to deal with during their stay in hospital.

Associated with the beliefs they held and the perceived uncertainties, staff were unable to adjust to suit these different coping strategies. Rather they relied upon their beliefs and assumptions that patients had no desire to confront the facts. Even explicit questions about cancer or expressed concerns about themselves were not taken as serious attempts by patients to deal with their situation by acquiring the facts about it or attempting to resolve their concerns through discussion. That so many patients were not open about their illness sustained such communication practices.

Relatives, while less directly affected by the illness than were the patients, demonstrated similar adaptation patterns in terms of communication. While they were more likely to have been told formally that the illness was malignant, like patients, the onus was on them to seek such information. A substantial number had no contact with hospital staff within Radiotherapy, at the place of diagnosis or with their General Practitioner. Not all relatives chose to seek definite information, a number realising the nature of the illness from their own lay knowledge and others preferring to remain in a state of uncertainty over diagnosis and prognosis. They relied on the same adaptive mechanisms as did patients, of selective information seeking and avoidance with information appraisal according to the threat it contained. Unlike patients, relatives had been given a possible time scale as a prognosis but on the whole prognosis was couched in more

optimistic terms than the facts justified.

Some relatives were subject to psychosocial distress, sometimes of a severe nature. This was particularly so when a poor prognosis was recognised and when sources of support were not available. Unlike patients who were able to share some of their concerns with fellow patients, some relatives suffered in isolation and were unable to share their problems as a means of coping. The restricted nature of contact with hospital staff for those who established it and the absence of professional contact with nurses for most relatives meant that they had minimal support from this source.

Discussion

The data obtained through observation and interviewing can be taken simply as descriptive of events as they happened in the Department studied. However the interpretation placed on the data goes beyond the specific environment studied to indicate processes and problems which have wider relevance for hospitals as the complex organisations within which care is delivered and for the staff and patients who are involved in them. In this sense the study can be regarded as complementary to other studies of communication in hospitals and in identifying and analysing practices and attitudes which have a bearing on patient care.

Hall says '... observations and theory are intertwined, for if observations are essential elements in the development and validation of theory, so theory acts to structure and make understandable the observations' (2, p.185). Theory influences both the sort of observations made and the interpretations of such observation. Asking questions about cancer may be interpreted as a natural and therapeutic response to it or as a maladaptive and potentially harmful activity. In the

present study information seeking was interpreted in the light of the construction the patient was trying to place on his illness and the management of uncertainty about it. Behaviour associated with information seeking therefore was interpreted in the light of a dynamic response to the illness as well as patients' beliefs about cancer in general and their own illness in particular. However it was sometimes believed by nurses that information seeking and expressions of awareness were harmful to the patient and this was used as an argument for avoiding talk about the illness. This was reinforced when emotional responses accompanied information giving. Data bear out that some patients were distressed about their illness but this distress was expressed in different forms. To interpret distress which shows as disturbance in the direction of increased emotional expression as indicative of a maladaptive response overlooks the fact that patients who show distress by withdrawing or avoiding the issue may be equally disturbed. Similarly the immediacy of such an interpretation of demonstrated emotion avoids consideration of longer term outcomes.

It is important therefore to consider the link between theory and the pursuit of data. The broad aim of the study was to find out about communication associated with cancer but it is apparent that the findings have implications for the study of communication in general in hospital wards and for the development of theoretical models of adaptation to illness. At the outset the study was assisted by other studies of hospitals as well as by studies of the management of uncertainty in illness. Developments suggest that while the careers of individual patients provide valuable data, it is also important to focus attention on the processes of interaction between groups of participants. This demonstrated that the whole ward context is an appropriate unit to observe how individuals make their unique adjustments. Adaptation of

the individual is viewed within the whole social context of the ward.

By examining and giving equal weight to the contribution of all participants this permits an understanding of their mutual influence. Thus as well as considering the meaning of events for patients, it was equally important and relevant to attempt to ascertain why doctors and nurses acted as they did as well as the role of others - relatives, radiographers, physiotherapists and so on - in the ongoing social milieu. As well as patients having problems in coping with cancer, it was equally evident that so had hospital staff. It was apparent however that staff were concerned to maintain the social order of the ward and carry on their work to perpetuate this. Thus the ward can be viewed as a social arena within which interaction takes place with participants showing cooperation and competition as they cope with being patients or hospital staff.

Why did participants act in the manner observed? Interviews and informal discussion provided accounts by the individuals themselves but can these really be taken as 'honest' or complete explanations? There was no suggestion that there were deliberate attempts to mislead or conceal what the individuals themselves regarded as their motives. But there is no way of absolutely verifying this. Motivation is complex, operating at conscious as well as subconscious levels, thus precluding complete and rational explanations of the basis for action. Even if it was possible to articulate what are considered as motives, there is no way of ascertaining whether in fact these represent 'real' motives or some acceptable but unconscious rationalisation of them. There is unlikely to be any single explanation of behaviour. Rather it is complicated by a combination of desires, beliefs and attitudes. Not only are processes within the individual operative, action is constrained also by the social context within which it takes place.

In the hospital context studied, nurses' accounts indicated that they regarded factors like lack of time and the absence of privacy as constraining factors on their communication with patients. No doubt they were, yet when these were available communication practices did not change. The nature of interactions themselves influenced participants actions. The likelihood of patients raising questions or problems and the persistency with which these could be pursued was influenced not only by the individuals involved but by staff's management of the tone of the interaction, placing limits on development. Although patients said they intended to find out, the presence of others, the way in which their questions were dealt with and the degree of control exerted in the situation by staff made further questioning seem inappropriate, influenced the kind of questions eventually asked and ultimately, the information received. Similarly patients became aware that nurses avoided talk about the illness, they set the level of communication and so exerted a degree of control within interactions which made certain topics seem inappropriate.

Nurses offered reasons for avoiding learning about patients' concerns. They did not know what to say, not because they lacked the facts, but because they did not know how to communicate without risking upsetting patients. As well as fearing emotional outbursts by patients, they also had no wish to encounter the emotion such conversations gave rise to within themselves. Becoming acquainted with patients predisposed to forming attachments with them which as well as being 'unprofessional' also risked hurting the nurse by forcing a realisation of what the patient was facing. Openness would also have influenced the whole emotional tone of the ward. These factors were all involved. Nurses offered no conscious conceptualisation or plan of what they hoped to achieve through communication, apart from a desire to cause the patient

no distress and maintain their hope. Accordingly they did not recognise potential useful or harmful effects.

The complexity makes it impossible to establish with absolute certainty the basis for action. Yet there was a high degree of consistency between how hospital staff said they communicated and what was observed to happen. Apart from both nurses and doctors assertion that communication depended on individual patient assessments, there was no major disparity between what was observed and what was said to happen. Similarly among patients and relatives - those who said they had no wish to learn the facts of their illness avoided making efforts to do so, while those who said they wanted to know sought to establish the facts. Thus the reasons advanced for action by all participants can be reasonably accepted as valid while retaining the proviso that these may not be the only reasons.

Differences in the way patients coped could not be accommodated by nurses and doctors. While uncertainties account for much of the explanation, also important was the urge to preserve continuity in the social order of the ward. If patients asked nurses, the significance and status of their questions was not fully assessed nor were patients' desires passed on to doctors. There was little point in doing so for they held no significance. Neither did nurses see any point in sharing such communication with each other.

So long as patients showed no desire to be open, this was aided by the methods of communication employed and there was no challenge to order. When patients were ready to proceed to a more explicit form of communication it was here that challenges became apparent and had to be controlled. While patients were able to obtain information and support informally, they could not easily obtain it from professionals. Of course, had staff been involved in open communication when patients sought it, they could have been asked to provide the support necessary to handle it. Nurses felt unable to do so and avoided risking being

placed in such a position. Continuity and preservation of the established order was thus ensured.

Information about the illness is only one aspect of communication yet it is the one which has received most attention. This is particularly so in terms of patients' complaints about insufficient information and, for cancer, whether the doctor should tell. In the present study with a heterogeneous patient group it was evident that many patients knew at least their diagnosis and so did not require to be told. They had to adjust to what that conveyed to them however and many patients appeared to define their situation with a degree of optimism. While some patients were pessimistic, they could have been pessimists even without having cancer but some were obviously affected by their illness. Patients who were so distressed may have been benefitted by discussing their concerns with staff. Fears need not lie in the prospect of no recovery, but in issues like the control of pain or concern over those left behind. To discuss such matters does not involve disclosure but acknowledgement and a willingness to stay and listen.

Many patients were uncertain - they were not prepared to seek confirmation and it was not offered. Should patients who suspected the truth have been told? There seems no reason to confront patients with information they are not prepared to handle. Weisman writes 'successful coping requires a balance between what one can accept or confront, and what can be harmlessly ignored or postponed' (3, p.13). While patients who suspect may not want to know, others show a changing pattern of communication indicating an increasing desire to confirm their suspicions. Patients also began to seek professional confirmation for what they have already gathered informally. This would suggest that it is not only information that they seek, but a degree of mutuality with those charged with managing their illness. This was sought through

both nurses and doctors. If it is not feasible to give the emotional support required to handle information, then, in the context observed, staff were probably right in not becoming involved in disclosure.

However when patients make it obvious that they know and seek confirmation, not disclosing, raises questions of the kind of trust patients can place in staff.

For patients who gave no indication of wishing to learn the facts of their illness there seems to be no point in telling them. If they were informed some would simply deny having been told⁽⁴⁾. Others are indicating that they are not ready to confront the facts. The equilibrium between acceptance and denial is likely to change however in response to what the patient cannot help learning and even denial may be only a temporary manifestation.

One can sympathise with staff over their difficulties in assessing what patients wished to know and how they sought to manage their illness. They did not hold the same doubts that relatives should be informed so long as they initiated interaction. Of course relatives differ in that they do not have the illness themselves and, while they would hold the same lay beliefs about cancer as would patients, the implications need not be so profound. It would seem that over successive interactions, with a willingness to be receptive to the cues patients emit, indications are available of how much patients want to know. In this event, telling would be unlikely to precipitate the catastrophic emotional reactions feared while it would be unusual, and perhaps pathological, if some distress was not shown.

The study focussed on information rather than other aspects of adaptation and interaction. But it was apparent that some patients talked about their illness not only to obtain information to define and redefine their situation but also to relieve stress. Nurses knew this,

but avoided such encounters. Should they have done so? There would seem no point in forcing a patient to confront his illness against his will but openness for many would seem to be integral to adjustment, part of the 'process of realisation'.⁽⁵⁾ Other patients are invaluable as an outlet for expression, but they cannot always provide the help patients seek, particularly in adapting to new circumstances created by matters like surgery, or the disability created by the illness. It would seem beneficial if professional help could supplement such lay support. To do so however nurses themselves would require help to manage such an innovation. It may be that other patients are isolated and withdrawn for reasons associated with their illness and hospitalisation. Such withdrawal may be symptomatic of other underlying problems for which remedies are available. Nurses fear openness however, not only for fear it upsets the patient concerned, but that other patients would also be affected. It is possible to contrive privacy to explore such matters.

Tailoring communication to meet such different needs and patterns of adaptation may be interpreted that, just as nurses and doctors said, communication should be individualised. As it was, routines based on typifications were important and demanded only knowledge of features of the diagnosis and current treatment. A typology based on different patient characteristics may be more appropriate in refining and elaborating appropriate communication practices. Knowledge is now becoming available in this complex subject from such diverse fields as cancer care, dying, bereavement, adjustment^{ment} and coping, chronic illness. In nursing and medicine, there is a commitment to action, to the management of patients through interventions which will produce change in desirable directions. The present study indicated that the direction which communication attempted to attain, however, was one of avoidance and minimisation of the illness. This fitted what staff considered patients want and need.

Obviously such decisions include value judgements. It would now seem appropriate to use available knowledge on which to base such judgements as well as principles of practice. It should be possible to begin to develop typologies of patients with sufficient information about each type of problem to develop generalisations and hence treatment. Again however we are compelled to return to resistance to such different forms of operating.

Implications for Nursing

Nurses universally agreed that communication is an important aspect of nursing. However they disagreed regarding the form such communication should take and the relative value to patients of openness. The pressure on nurses to devote their time to nursing care associated with physical needs was strong. Observation showed communication to be one of the lowest priorities, especially when nurses were busy. But even when time allowed they lacked the inclination, knowledge and experience to take advantage. They were hindered in developing any sense of purpose in communication or that different forms of communication had different contributions to make.

Unless it is recognised that communication with patients about their illness is of value, and appropriate education is provided, it is unrealistic to expect nurses to alter the role for which they have been trained and around which work is organised. The emphasis on the physical reduces sensitivity to other components of patient care. While the above argument seems fundamental to any development, the total social environment also requires consideration. The key issues of the emotional implications of working with cancer patients, accountability for communication and the nurse's role in this aspect of care are inter-related. Change in one depends on and is likely to

influence the others. The problem must take account of resistance to such change.

Working in a radiotherapy department meant that nurses could not avoid the strong emotions evoked by cancer. They could not switch their attention to patients with less threatening illness although they could select patients for attention who were unlikely to raise illness related topics. Nevertheless they could not evade the illness altogether nor the strong association between cancer and dying. This was evident in how nurses talked about the illness. They became upset when treatment efforts were prolonged with no apparent benefit to the patient, when untimely and lingering deaths occurred, when patients expressed their fears. They were uncomfortable when they saw the patients' outlook as hopeless and when patients themselves came to recognise that their illness would be fatal.

There were no opportunities for nurses to share their feelings or the difficulties they encountered. Experiencing such reactions made some nurses feel guilty - that they were somehow different from other nurses and 'unprofessional'. As a result they were disinclined to show emotion, express their difficulties or seek help from ward colleagues. As a first step in developing an ability in nurses to interact with and listen to patients who express their concerns, nurses would seem to require assistance to cope with their own discomfort. They require opportunities to express how they feel in a supportive and uncritical environment. They also require assistance with how to manage what they regard as difficult interactions. They require help to recognise that hope need not lie only in life but in the quality of remaining life. While they may be helpless to prolong life they need not be helpless in maintaining the patients' hope, whatever the source of that hope may be.

Recognition that nurses and doctors as well as patients and their families have emotional needs may go some way towards developing a more therapeutic environment. Assistance in providing it may come not only from nurses and doctors with appropriate experience but also from other services - pastoral and psychiatric. In fact during the course of the study a hospital chaplain offered to be available to nurses to discuss some of the difficulties they encountered in the ward. Nurses did not recognise how this could be useful, considering they discussed such matters adequately. Its threat to disrupt the manner in which nurses managed their problems was sufficient to cause the offer to be rejected. Such supportive intervention in a cancer service has been shown elsewhere to increase the morale of nurses and patients as well as influence communication practices⁽⁶⁾ but this raises the question of the preconditions for such innovation.

It was evident nurses feared making mistakes in their communications. They were afraid of doing or saying the wrong thing - afraid of the doctors' reaction as well as the patients'. One way to avoid appraisal of communications was to keep them private. Thus nurses did not share their experiences with patients with each other. It was not regarded as important. Yet some young nurses said that they would have welcomed an opportunity to do so. Through openness nurses could have learned how they were managing patients and may have been able to develop skills by learning from those who had them. This applies as much to assisting relatives as patients. Student nurses did not have opportunities to talk with relatives, except socially, yet were expected to be able to do so on registration. As well as passing on currently available skills, making communication explicit has implications for the development of nurses' awareness of the specific uncertainties associated with particular patients with the potential for their reduction.

Communication practices could also be influenced by changes in

nurses' interaction patterns. The data demonstrated how little interaction some patients had with nurses and how little some nurses reported knowing about their patients, far less their families. The problem was exacerbated when patients did not require physical care and nurses saw no legitimate reason for introducing patient contact. Nurses could benefit from learning how to be comfortable with patients who demonstrate no physical needs and be released from feeling that they should be engaged in some physical activity. It was apparent from patients' and relatives' comments that they would have welcomed the opportunity for greater contact with nurses. They appreciated what nurses did and their pleasant manner. Of course shortage of time was part of the problem. Changes in ward management such that nurses had fewer patients in their charge would have reduced the number with whom each had to become familiar as well as saving time. They would not have had to listen to reports of over fifty patients or walk so far. For patients who require no physical care it may have helped to designate a nurse with responsibility for their particular needs, ensuring that they would not be overlooked because they presented no physical work. Changes in interaction patterns in themselves however would not necessarily influence communication practices.

The whole issue of communication in the care of cancer patients has obvious implications for nurse education at both basic and post-basic levels. Nurses believed communication could not be taught. They also stressed that patients' individuality precluded prescriptions in this area. Their knowledge of social sciences was limited to a few general psychology lectures in their introductory period. Some appreciated the need for a 'psychological' approach to patients but felt they lacked the skill to carry this out. They were aware of learning by trial and error and modelling their behaviour on more senior nurses. There would seem to be a need to consider how to teach topics

associated with adaptation to illness in general and cancer in particular. This applies to both formal and clinical teaching. Education would require to focus not only upon the substantive aspects of providing care but also on issues like the appraisal of nurses' responsibilities in assisting patients and their families to cope with the social and psychological problems likely to accompany serious illness as well as physical problems. Communication about illness requires to be set within such a broad context if it is to have relevance for diverse patient groups.

Of course nurses do not work in isolation. Particularly they are influenced by their medical colleagues. Where communication was concerned nurses tended to shield behind the doctors' authority position. Changes in communication would depend on nurses developing their own sense of professional accountability and willingness to develop and show competence in this aspect of their work. However a greater measure of cooperative planning and mutual support between nurses and doctors would be called for.

Implications for Future Research

This study can be regarded as making contributions to the fields of communication in hospital and to processes of adjustment to illness. Comparative studies of the management of communication with different patient categories and in different social environments would add to knowledge about this under-developed aspect of nursing. Equally important would be investigation into the effects of attempts to introduce change - in developing more therapeutic ward environments - with attention to sources of resistance to change as well as facilitation of such innovations. In this sense research in nurse education

about communication or introducing changes in accountability would be usefully set within broader attention to the social milieu within which such education takes place.

This study examined patients' adjustment to cancer in terms of communication during a short spell in their patient career. It would be useful to consider longitudinal assessment over the whole career, comparing and contrasting not only different types of cancer but also different career patterns. Cancer can take very varying courses and it may be useful to compare those with early curable cancers with those whose illness follows a more progressive course. This would entail several hospitalisations as well as coping at home.

At the moment reluctance to tell and the assessment of unfavourable responses to knowing are associated with pessimistic lay conceptions of cancer. Nurses said they could not change their pattern of communication until there were first changes in public opinion. Yet the practice of not telling and avoiding openness perpetuates such beliefs, acknowledging that staff too see cancer in this light. It is patients who die that nurses remember, and it is they who make news. It would be useful to monitor the reactions of patients with curable cancers to being told. Similarly studies in hospitals in which there is greater openness about cancer would provide useful comparative data on the implications of such practices for patients and staff alike.

In Conclusion

The emotional difficulties experienced during this study were a poignant indication of the problems encountered by patients, their families and hospital staff. In attempting to describe and explain communication the aim was to aid nurses' understanding of such problems. No criticism of those involved was intended in displaying their practices. However a completely rational and non-judgemental stance is difficult

by one who has been involved in similar situations as a nurse and then looks on from the side lines as a helpless but non-the-less involved research worker. It is to be hoped that the evidence presented will have some relevance both practical and theoretical, for those whose difficult task it is to care for cancer patients and their families.

References

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DATA COLLECTION SHEET FOR OBSERVATION PERIOD 2

| | | | |
|----------|----------------|------------|---------|
| DATE: | NURSE(S) NO: | INITIATOR: | OTHERS: |
| INT. NO: | PATIENT(S) NO: | DURATION: | TYPE: |

VERBATIM REPORT BY NURSE NO: _____

OTHER COMMENTS:

APPENDIX IIPATIENTS' CHARACTERISTICSOBSERVATION PERIOD 1

| Patient Number | Sex | Age | Diagnosis | Number of days in ward during observation | Physical dependency category |
|----------------|--------|-----|----------------------------|---|------------------------------|
| 1 | Male | 65 | Ca. bronchus | 2 | D |
| 2 | Male | 29 | Seminoma | 31 | E |
| 3 | Male | 36 | Lymphosarcoma of abdomen | 31 | E |
| 4 | Male | 74 | Ca. bronchus | 8 | D |
| 5 | Male | 13 | Osteosarcoma | 30 | D |
| 6 | Male | 58 | Hodgkin's Disease | 8 | A |
| 7 | Male | 73 | Seminoma | 23 | E |
| 8 | Female | 79 | Ca. breast with metastases | 18 | B |
| 9 | Female | 64 | Ca. breast | 26 | E |
| 10 | Female | 57 | Ca. Oesophagus | 18 | D |
| 11 | Female | 44 | Ca. breast with metastases | 6 | C |
| 12 | Female | 61 | Ca. uterine cervix | 17 | E |
| 13 | Female | 47 | Rodent ulcer | 5 | E |
| 14 | Female | 76 | Ca. breast with metastases | 5 | D |
| 15 | Female | 58 | Ca. uterine cervix | 3 | E |

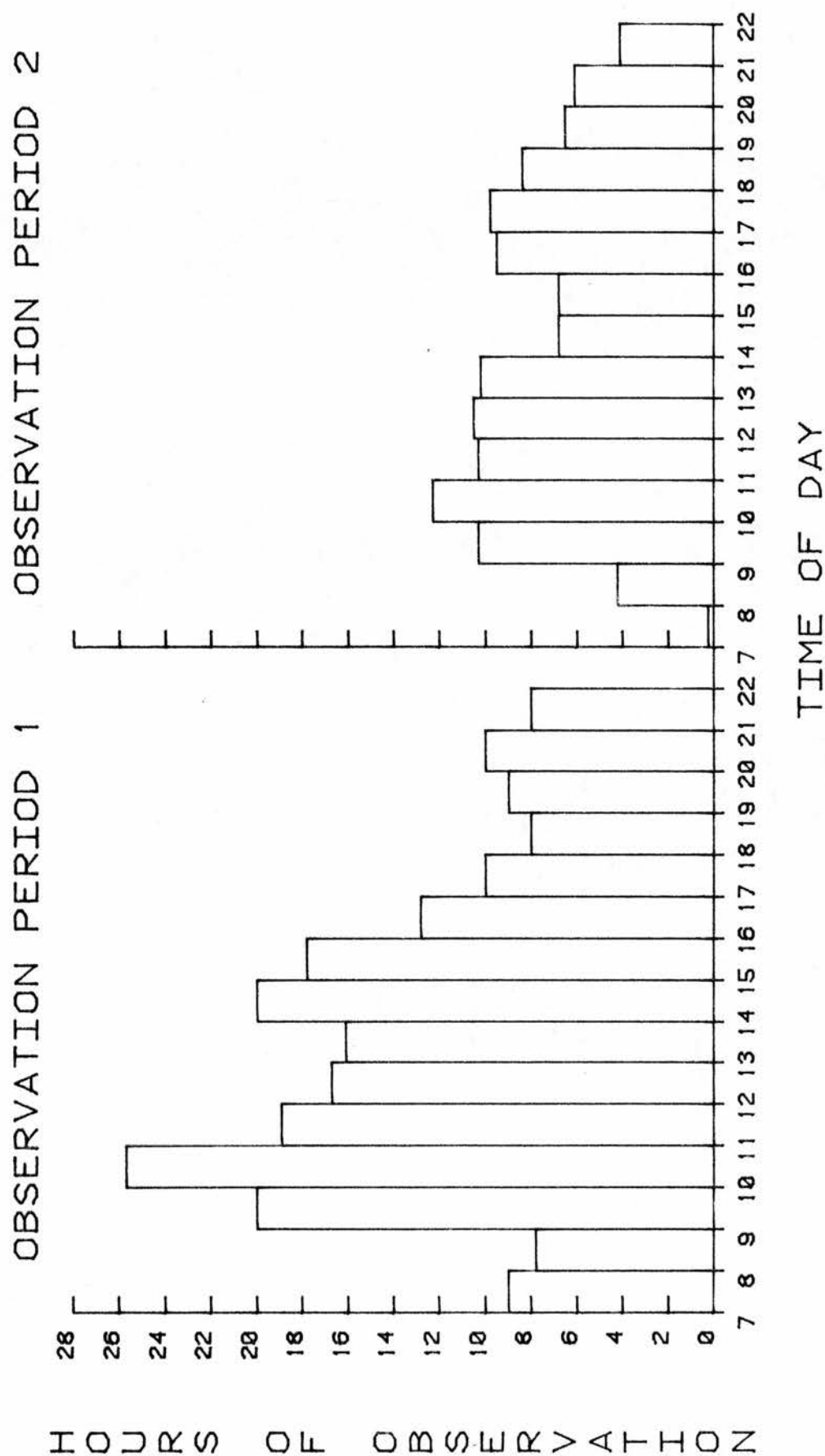
OBSERVATION PERIOD 2

| Patient Number | Sex | Age | Diagnosis | Number of days in ward during observation | Physical dependency category |
|-------------------|--------|-----|---------------------------------|---|------------------------------------|
| 16 | Female | 55 | Ca. uterine cervix | 3 | E |
| 17 | Female | 68 | Ca. oesophagus | 8 | E |
| 18 | Female | 50 | Ca. oesophagus | 6 | E |
| 19 | Female | 71 | Ca. uterus | 25 | E |
| 20 | Female | 68 | Ca. breast | 3 | E |
| 21 | Female | 86 | Ca. skin | 11 | D |
| 22 | Male | 70 | Ca. bronchus | 9 | E |
| 23 | Male | 64 | Ca. bladder and Ca. bronchus | 15 | C |
| 24 | Male | 82 | Ca. bladder | 27 | C |
| 25 | Female | 50 | Ca. uterine cervix | 17 | D |
| 26 | Male | 75 | Ca. bronchus | 27 | D |
| 27 | Male | 77 | Ca. tongue | 8 | E |
| 28 | Male | 77 | Ca. soft palate | 4 | D |
| 29 | Male | 70 | Ca. maxillary antrum | 16 | E |
| 30 | Female | 62 | Ca. uterine cervix | 22 | B |
| 31 | Male | 70 | (Boarder) | 2 | B |
| 32 | Female | 55 | Ca. uterine cervix | 12 | D |
| 33 | Male | 71 | Ca. bronchus | 6 | D |
| 34 | Female | 78 | Ca. oesophagus | 9 | D |
| 35 | Male | 80 | Ca. bronchus | 8 | D |
| 36 | Female | 65 | Ca. uterine cervix | 12 | E |
| 37 | Female | 66 | Ca. breast | 4 | E |
| 38 | Male | 37 | (Boarder) | 1 | B |
| 39 | Male | 74 | Ca. anus | 19 | D |
| 40 | Male | 54 | Ca. bronchus | 16 | E |

Observation Period 2 cont'd.

| Patient Number | Sex | Age | Diagnosis | Number of days in ward during observation | Physical dependency category |
|----------------|--------|-----|----------------------------|---|------------------------------|
| 41 | Male | 64 | Ca. bladder | 16 | E |
| 42 | Female | 34 | Ca. breast with metastases | 15 | B |
| 43 | Female | 55 | Ca. breast with metastases | 15 | B |
| 44 | Female | 68 | (Boarder) | 3 | C |
| 45 | Male | 68 | Ca. bronchus | 7 | E |
| 46 | Male | 53 | Ca. oesophagus | 12 | E |
| 47 | Male | 69 | Ca. mouth | 12 | E |
| 48 | Female | 59 | Ca. uterus | 11 | D |
| 49 | Female | 54 | Ca. uterine cervix | 7 | E |
| 50 | Female | 65 | Ca. bronchus | 11 | C |
| 51 | Female | 71 | Ca. breast with metastases | 11 | B |
| 52 | Female | 62 | Ca. uterine cervix | 6 | D |
| 53 | Male | 52 | Ca. bronchus | 5 | E |
| 54 | Female | 69 | Post Cricoid Ca. | 4 | D |
| 55 | Male | 26 | Seminoma | 4 | E |

FIGURE _{III}. DISTRIBUTION OF OBSERVATION TIME



APPENDIX IVTABLE II PERCENTAGE PATIENT INTERACTION TIMES FOR
OBSERVATION PERIODS 1 AND 2

| Number of patients with % Int. Time | Period 1 | Period 2 | Total Patient Sample | % |
|--|-------------|-------------|----------------------------|-------|
| Less than 1.0% | 8 | 21 | 29 | 53.7 |
| 1.0% but less than 2.0% | 2 | 8 | 10 | 18.5 |
| 2.0% but less than 4.0% | 3 | 6 | 9 | 16.7 |
| 4.0% or more | 2 | 4 | 6 | 11.1 |
| | 15 | 39 | 54 | 100.0 |

TABLE III PATIENT INTERACTION TIMES FOR OBSERVATION
PERIODS 1 AND 2

| Number of patients with Int. Time | Period 1 | Period 2 | Total Patient Sample | % |
|--------------------------------------|-------------|-------------|----------------------------|-------|
| Less than 15 mins. | 2 | 17 | 19 | 35.2 |
| 15 mins. but less than 60 mins. | 11 | 17 | 28 | 51.9 |
| 60 mins. but less than 120 mins. | 1 | 1 | 2 | 3.7 |
| 120 mins. or more | 1 | 4 | 5 | 9.2 |
| | 15 | 39 | 54 | 100.0 |

TABLE VIII COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR ALL INTERACTIONS ABOVE AND
BELOW THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 9 | 17 | 26 |
| Female | 18 | 10 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 6.00; \text{d.f.} = 1; p > .02$$

TABLE IX COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR INTERACTIONS LASTING LESS
THAN 3 MINUTES ABOVE AND BELOW THE MEDIAN FOR
THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 10 | 16 | 26 |
| Female | 17 | 11 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 3.63; \text{d.f.} = 1; p > .05$$

TABLE X COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR INTERACTIONS LASTING 3
MINUTES OR MORE ABOVE AND BELOW THE MEDIAN FOR
THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 9 | 17 | 26 |
| Female | 17 | 11 | 28 |
| | 26 | 28 | 54 |

$$x^2 = 4.79; \text{d.f.} = 1; p < .05$$

Patients falling on the median are classified with those below it.

TABLE XI COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION TIMES ABOVE AND BELOW THE MEDIAN FOR
THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 8 | 18 | 26 |
| Female | 19 | 9 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 8.97; \text{d.f.} = 1; p < .02$$

TABLE XII COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
PERCENTAGE INTERACTION TIMES ABOVE AND BELOW THE
MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 7 | 19 | 26 |
| Female | 20 | 8 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 12.54; \text{ d.f.} = 1; p < .001$$

TABLE XIII COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR ALL DYADIC INTERACTIONS
ABOVE AND BELOW THE MEDIAN FOR THE TOTAL PATIENT
SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 7 | 19 | 26 |
| Female | 17 | 11 | 28 |
| | 24 | 30 | 54 |

$$x^2 = 6.33; \text{ d.f.} = 1; p < .02$$

Patients falling on the median are classified with those below it.

TABLE XIV COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR DYADIC INTERACTIONS LASTING
LESS THAN 3 MINUTES ABOVE AND BELOW THE MEDIAN FOR
THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 9 | 17 | 26 |
| Female | 18 | 10 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 6.00; \text{d.f.} = 1; p < .02$$

TABLE XV COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION RATES FOR DYADIC INTERACTIONS LASTING
3 MINUTES OR MORE ABOVE AND BELOW THE MEDIAN FOR
THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 5 | 21 | 26 |
| Female | 17 | 11 | 28 |
| | 22 | 32 | 54 |

$$x^2 = 11.40; \text{d.f.} = 1; p < .001$$

Patients falling on the median are classified with those below it.

TABLE XVI COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
INTERACTION TIMES FOR DYADIC INTERACTION ABOVE
AND BELOW THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 5 | 21 | 26 |
| Female | 19 | 9 | 28 |
| | 24 | 30 | 54 |

$$x^2 = 12.76; \text{d.f.} = 1; p < .001$$

Patients falling on the median are classified with those below it.

TABLE XVII COMPARISON BETWEEN MALE AND FEMALE PATIENTS WITH
PERCENTAGE INTERACTION TIMES FOR DYADIC INTERACTIONS
ABOVE AND BELOW THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Patient sex | Number of patients above median | Number of patients below median | Total number of patients |
|-------------|---------------------------------|---------------------------------|--------------------------|
| Male | 6 | 20 | 26 |
| Female | 21 | 7 | 28 |
| | 27 | 27 | 54 |

$$x^2 = 16.69; \text{d.f.} = 1; p < .001$$

TABLE XVIII COMPARISON BETWEEN PATIENTS IN DIFFERENT DEPENDENCY
CATEGORIES WITH INTERACTION RATES FOR ALL INTERACTIONS
ABOVE AND BELOW THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Dependency Category | Number of patients above median | Number of patients below median | Total number of patients |
|---------------------|---------------------------------|---------------------------------|--------------------------|
| ABC | 8 | 5 | 13 |
| D | 9 | 8 | 17 |
| E | 10 | 14 | 24 |
| | 27 | 27 | 54 |

$$x^2 = 1.36; \text{ d.f.} = 2; p > .05$$

TABLE IXX COMPARISON BETWEEN PATIENTS IN DIFFERENT DEPENDENCY
CATEGORIES WITH INTERACTION RATES FOR INTERACTIONS
LASTING 3 MINUTES OR LONGER ABOVE AND BELOW THE
MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Dependency category | Number of patients above median | Number of patients below median | Total number of patients |
|---------------------|---------------------------------|---------------------------------|--------------------------|
| ABC | 11 | 2 | 13 |
| D | 8 | 9 | 17 |
| E | 7 | 17 | 24 |
| | 26 | 28 | 54 |

$$x^2 = 10.38; \text{ d.f.} = 2; p < .01$$

Patient falling on the median is classified with those below it.

TABLE XX COMPARISON BETWEEN PATIENTS IN DIFFERENT DEPENDENCY
CATEGORIES WITH INTERACTION TIMES ABOVE AND BELOW
THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Dependency category | Number of patients above median | Number of Patients below median | Total number of patients |
|---------------------|---------------------------------|---------------------------------|--------------------------|
| ABC | 11 | 2 | 13 |
| D | 8 | 9 | 17 |
| E | 7 | 17 | 24 |
| | 26 | 28 | 54 |

$$x^2 = 10.38; \text{d.f.} = 2; p < .01$$

Patient falling on the median is classified with those below it.

TABLE XXI COMPARISON BETWEEN PATIENTS IN DIFFERENT DEPENDENCY
CATEGORIES WITH PERCENTAGE INTERACTION TIMES ABOVE
AND BELOW THE MEDIAN FOR THE TOTAL PATIENT SAMPLE

| Dependency category | Number of patients above median | Number of patients below median | Total number of patients |
|---------------------|---------------------------------|---------------------------------|--------------------------|
| ABC | 11 | 2 | 13 |
| D | 7 | 10 | 17 |
| E | 9 | 15 | 24 |
| | 27 | 27 | 54 |

$$x^2 = 8.26; \text{d.f.} = 2; p < .02$$

TABLE XXII **COMPARISON BETWEEN NUMBERS OF MALE AND FEMALE**
PATIENTS IN EACH DEPENDENCY CATEGORY

| Patient sex | Category ABC | Category D | Category E | Total |
|----------------|-----------------|---------------|---------------|-------|
| Male | 5 | 8 | 13 | 26 |
| Female | 8 | 9 | 11 | 28 |
| | 13 | 17 | 24 | 54 |

$$\chi^2 = 0.81; p > .05$$

APPENDIX

FACILITIES FOR VISITORS TO THE DEPARTMENT
OF RADIOTHERAPY,

This questionnaire is being given to visitors to the Department of Radiotherapy,, to help provide some information about facilities provided for the family and friends of patients. It is part of a larger study about patient care.

We are constantly trying to evaluate services given in hospitals and would welcome any suggestions or comments you have to make. By answering the questions set out below you will help us to gain a better understanding of your opinions.

All the information given will be treated in the strictest confidence, no names will be used.

Your co-operation in completing and returning this questionnaire will be very much appreciated.

Mrs. Senga Bond,
Nursing Research Unit,
Department of Nursing Studies,
University of Edinburgh.

1. What is your relationship to the patient? (Tick one)

Next of kin.....

☐

Other.....

☐

If 'Other', please say what (e.g. friend, daughter)

.....

2. In your opinion, are visiting hours in the department (Tick)

too long.....

☐

too short.....

☐

just right.....

☐

at inconvenient times.....

☐

3. Do you think that any alteration in visiting hours is necessary?
If so, what do you suggest?

.....

.....

.....

4. In your opinion, visiting the hospital (Tick one or more)

is no problem at all.....

☐

is a long way to travel.....

☐

means using inconvenient
transport.....

☐

is difficult with children.....

☐

involves loss of work.....

☐

is expensive.....

☐

is well worth any inconvenience
caused.....

☐

5. When you are visiting the patient, do you feel there is (Tick one)

enough privacy

☐

not enough privacy

☐

6. Does the patient you are visiting go home at weekends? (Tick one)
- | | |
|-----------------|--------------------------|
| Always..... | <input type="checkbox"/> |
| Sometimes..... | <input type="checkbox"/> |
| Never..... | <input type="checkbox"/> |
| Don't know..... | <input type="checkbox"/> |

If you answered never or don't know, please carry on at question 9.

If you answered always or sometimes, please carry straight on.

7. When the patient goes home for the weekend, does this (Tick one or more)
- | | |
|--|--------------------------|
| make the rest of the time in hospital more pleasant for him/her..... | <input type="checkbox"/> |
| create more expense that if he/she stayed in hospital..... | <input type="checkbox"/> |
| give the patient something to look forward to... | <input type="checkbox"/> |
| unsettle him/her..... | <input type="checkbox"/> |
| create transport problems..... | <input type="checkbox"/> |
| make the family and/or the patient anxious about the treatment or medicines..... | <input type="checkbox"/> |
| make home seem more 'normal'..... | <input type="checkbox"/> |

If you have experienced any other effects of weekends at home on the patient or the family, please say what these are.....

.....

.....

8. Officially patients who go home at weekends do not leave the ward until 4 p.m. on Friday and should return by 8 p.m. on Sunday evening. Have you any suggestions to make about departure or return times?
-
-
-
-

THIS SECTION IS CONCERNED WITH FACILITIES FOR SEEING MEDICAL STAFF.

9. Many of the patients admitted to this department have recently been in other hospitals. Had you already spoken with a doctor about the patient's current illness before he/she was admitted to this ward?
(Tick one)

Yes.....

☐

No.....

☐

10. As far as you know, has any other member of the patient's family or friends spoken with a doctor prior to the patient's admission?
(Tick one)

Yes.....

☐

No.....

☐

Don't know.....

☐

11. Since the patient has been in this department, have you felt at any time that you would like to talk with a doctor about the patient?
(Tick one)

Yes.....

☐

No.....

☐

12. Have you already spoken with a doctor from this department, either here or at an out-patient clinic?
(Tick one)

Yes.....

☐

No.....

☐

If you answered no, please carry on at question 19.

If you answered yes, please carry straight on.

13. How often have you talked with a doctor in this department?
(Tick one)

Once.....

☐

Twice.....

☐

More than twice....

☐

14. Which doctors did you talk to? Can you give their names or position?

Name:Position:

(Please tick)

..... Consultant.....

☐

..... Registrar.....

☐

..... House doctor.....

☐

..... Don't know.....

☐

15. How did you arrange to see a doctor? (Please tick)

Approached him/her yourself in the ward.....

☐

A member of the nursing staff made the arrangement for you.....

☐

Made an approach through the radiotherapy office...

☐

Made an approach by writing or telephoning.....

☐

Arranged to see the doctor at an out-patient clinic.....

☐

16. When you saw the doctor(s) did you discuss:- (Please tick one or more)

The patient's current illness.....

☐

The treatment the patient is having.....

☐

The length of stay in hospital.....

☐

How to look after the patient at home.....

☐

If you discussed other things, can you say what these were please?

.....

.....

.....

17. When you talked with the doctor did you feel:-

Yes

No

you were given enough information.....

☐
☐

things were fully explained.....

☐
☐

you understood what was said.....

☐
☐

18. If you would have liked more information, what in particular would you have liked to talk about?

.....

.....

19. Are there any comments you would like to make about facilities in the department for seeing medical staff?

.....

.....

.....

.....

THIS IS THE LAST SECTION.IT DEALS WITH FACILITIES FOR SEEING WARD NURSES.

20. Have you talked with any of the ward nurses about the patient? (Tick one)

Yes..... ☐

No..... ☐

If you answered No, please go to question 26.

If you answered Yes, please carry on with question 21.

21. Which nurse(s) was this? Can you write their name(s) or position please? (Please tick)

Name: or Position:-

..... Sister..... ☐

..... Staff nurse..... ☐

..... Student nurse..... ☐

..... Nursing auxiliary..... ☐

Don't know..... ☐

22. How many times have you talked with a nurse? (Tick one)

Once..... ☐

Twice..... ☐

More than twice..... ☐

23. When you spoke with the nurse(s) did you discuss:- (Tick where appropriate)

The patient's current illness..... ☐

How the patient was progressing..... ☐

Treatment..... ☐

Length of stay..... ☐

Discharge arrangements..... ☐

How to look after the patient at home..... ☐

Weekends at home..... ☐

If other, please say what this was.....

.....

.....

24. When talking with a nurse did you feel you:- (Tick one)
- Had enough information..... ☐
- Would have preferred a
fuller discussion..... ☐
25. How did you arrange to see a nurse about the patient? (Please tick)
- by going and asking a nurse to have a word with you.. ☐
- making an appointment to see the sister..... ☐
- the nurse asked to talk to you..... ☐
- at a special time set aside for seeing relatives..... ☐
- If other, please say what.....
.....
26. Are there any comments you would like to make about facilities for
visitors to see a nurse, or matters you would have liked to discuss
with a nurse?
.....
.....
.....
.....
27. Do you think, once the patient is discharged from hospital he/she
or the family would welcome a visit from a nurse?
(Tick one)
- Yes..... ☐
- No..... ☐
- Not sure..... ☐
- If yes, which one would you prefer?
- | | | | | | |
|-------------------|--------------------------|-----|--------------------------|-----|--------------------------|
| | Ward nurse | or, | District nurse | or, | Health visitor |
| (Please tick one) | <input type="checkbox"/> | | <input type="checkbox"/> | | <input type="checkbox"/> |

28. Any further comments you would like to make about facilities for visitors to this department which have not been dealt with, or about which you would like to say a bit more, would be very much appreciated.

I should like to thank you for your time and patience in filling in this questionnaire. The information will be of considerable value.

Please replace the completed questionnaire in the envelope and return it either to myself personally or to the tray at the nurses' desk in the ward. Should you require any further information about the questionnaire or would like to discuss it, then please do not hesitate to ask.

APPENDIX VTABLE XXVIII RELATIONSHIP TO PATIENT AND CONTACT WITH DOCTOR IN
RADIOTHERAPY FOR QUESTIONNAIRE SAMPLE

| Relationship to patient | Contact with doctor | No contact with doctor | Total |
|----------------------------|---------------------|------------------------|-------|
| Spouse | 21 | 42 | 63 |
| Other relative | 12 | 33 | 45 |
| | 33 | 75 | 108 |

$$\chi^2 = 5.63; \text{d.f.} = 1; p < .02$$

TABLE XXIX RELATIONSHIP TO PATIENT AND CONTACT WITH NURSE IN
RADIOTHERAPY FOR QUESTIONNAIRE SAMPLE

| Relationship to patient | Contact with nurse | No contact with nurse | Total |
|----------------------------|--------------------|-----------------------|-------|
| Spouse | 9 | 53 | 62 |
| Other relative | 18 | 27 | 45 |
| | 27 | 80 | 107 |

$$\chi^2 = 8.96; \text{d.f.} = 1; p < .01$$